Advances in Clinical and Medical Research

Genesis-ACMR-5(1)-72 Volume 5 | Issue 1 Open Access ISSN: 2583-2778

Rules of Engagement: "Strategies to Enhance Community Engagement in Cardiovascular Genetic Research among the Gullah Geechee"

Jennifer L. Caldwell^{1*}, and Fatimah L.C. Jackson²

^{1*}Director Public Health Genomics Laboratory, Pennington Biomedical Research Center, Louisiana State University, Baton Rouge, Louisiana 70810

²Department of Biology, College of Arts and Sciences, Howard University, Washington, D.C. 20059

*Corresponding author: Caldwell JL, Director Public Health Genomics Laboratory, Pennington Biomedical Research Center, Louisiana State University, Baton Rouge, Louisiana 70810

Citation: Caldwell JL, Jackson FLC. (2024) Rules of Engagement: "Strategies to Enhance Community Engagement in Cardiovascular Genetic Research among the Gullah Geechee". Adv Clin Med Res. 5(1):1-15.

Received: November 4, 2023 | **Published**: January 8, 2024

Copyright[©] 2024 genesis pub by Caldwell JL, et al. CC BY-NC-ND 4.0 DEED. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives 4.0 International License., This allows others distribute, remix, tweak, and build upon the work, even commercially, as long as they credit the authors for the original creation.

Abstract

Legacy African American populations are highly diverse genetically and culturally. Yet they are underrepresented as study participants in genetic registries and clinical trials. A major barrier to participation in genetics research is creating effective community engagement strategies that create bidirectional relationships and increase health literacy. Community centered approaches to public health and genomic research help to increase health education and raise health standards in often disenfranchised communities. Moreover, the higher prevalence of outcomes like cardiovascular disease, which are common in the Stroke Belt, may mask structural racism components that are unveiled in community level research. Through field work assessments and meta-analysis, the objective of this research is to examine community engagement goals and strategies that are beneficial in our Gullah Geechee case study. The Gullah Geechee are a micro ethnic group rooted in Coastal South Carolina who are considered to be key progenitors of Legacy African Americans. Their geographical location in the Deep South, their genetic composition, and their protracted historical experiences with Jim Crow prejudices make the

them an ideal population to develop community engagement protocols that can be an adaptable template for larger African American population. This article highlights how the overlap of biomedical researcher goals, community goals, and the goals of the study can work in tandem to create an environment of inclusion and transparency during genomic research. This technique serves to correct previous distrust and inappropriate conduct within African American communities. The findings generate actionable solutions to develop successful community engagement strategies and methods to increase African American participation in genomic research and clinical trials.

Keywords

African American populations; Health literacy; Genomic research; Clinical trials.

Introduction

Health disparities persistently plague Legacy African Americans in the United States. This population is disproportionately affected by a range of health issues, including cardiovascular diseases, stroke, cancer, asthma, influenza and pneumonia, diabetes, and HIV/AIDS [34, 1] Specifically, Legacy African Americans face a higher prevalence of cardiovascular diseases, encompassing various heart and blood vessel disorders such as coronary heart disease, cerebrovascular disease, peripheral arterial disease, rheumatic heart disease, congenital heart disease, and deep vein thrombosis and pulmonary embolism. Additionally, they bear a greater burden of co-morbidities such as obesity and diabetes, which exacerbate the impact of cardiovascular diseases. Consequently, cardiovascular diseases rank as the leading cause of death globally, with Legacy African Americans experiencing some of the highest rates of such diseases worldwide. Notably, among non-Hispanic Legacy African Americans aged 20 and above, 63% of men and 77% of women are classified as overweight [35], further escalating the morbidity and mortality associated with cardiovascular diseases. Certain regions within the United States, characterized by alarmingly elevated rates of cardiovascular diseases coupled with high levels of obesity and diabetes, stand out.

The Stroke Belt, a term applied to eleven southeastern states including Arkansas, Alabama, Indiana, Kentucky, Louisiana, Mississippi, Tennessee, Virginia, Georgia, North Carolina, and South Carolina [42] with South Carolina at its core, bears witness to a 10% increase in cardiovascular disease morbidity and mortality among long-term residents compared to the rest of the United States. Most of these states were historically part of the antebellum South, or the Black Belt, and still maintain significant concentrations of African-descended individuals. The ports in these coastal states served as crucial immigration hubs during the transatlantic slave trade and domestic slave trade, inflicting severe racial injustices on enslaved African Americans. Other studies have documented the persistence of racial disparities and adverse experiences for Legacy African Americans within the Stroke Belt, underscoring the need for focused attention [20,10].

Previous research attributes the enduring high prevalence of chronic diseases, especially cardiovascular diseases, among African Americans in the Stroke Belt to socioeconomic factors and the historical legacy of structural racism [7,27]. However, interdisciplinary strategies are required to comprehensively address African American health within the Stroke Belt. These strategies should encompass diverse urban and

rural centers, explore phenotypic and genotypic variations, identify trans generational sources of epigenomic changes, examine lifestyle diversity within vulnerable communities, and understand population stratification or substructure [17-19].

In 2020, the American Association of Family Physicians formally declared structural racism a public health emergency [41]. Acknowledging that federal programs need to better serve African Americans, the government is striving to eliminate structural racism, which perpetuates health disparities [9] a former American Public Health President, highlights racism as a system that unfairly advantages some individuals while disadvantaging others based on their phenotype [34]. The Institute of Medicine defines health disparities as "differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriation of intervention [32]." However, these studies fail to elucidate why Legacy African Americans continue to experience disparities related to cardiovascular disease phenotypes, leaving a critical question unanswered.

Cardiovascular disease phenotypes are complex disorders resulting from the interplay of genes and the environment across various levels of interaction, leading to diverse disease expression patterns. These complexities pose challenges in developing effective interventions [31]. Comorbidities and social structures interact and are often compounded by pre-existing genetic and epigenetic risk factors. Environmental and social factors perpetuating chronic diseases include limited access to healthcare professionals, inadequate inclusion in experimental clinical trials, community resistance to interventions developed outside their cultural context, and healthcare providers' lack of awareness of patients' social and cultural experiences affecting health status. Significant environmental factors, such as socioeconomic and ethnic segregation and the presence of food deserts due to economic disinvestment in marginalized communities, can increase comorbidity risks [20-22].

To address these structural limitations, interdisciplinary, community-engaged investigative approaches can offer holistic solutions to understand the multifaceted inheritance profiles of complex diseases, particularly in marginalized populations. Such populations often experience a disconnect between health providers, policymakers, and their own cultural and social backgrounds, leading to insufficient recognition or understanding of their unique needs. This knowledge gap is reflected in the limited sophistication of existing databases and the adoption of conclusions that fail to pinpoint the root causes of observed trends. Misguided information can lead to policies that perpetuate existing socioeconomic disparities. In light of the growing emphasis on racial equity for People of Color, the American Heart Association has introduced a new cardiovascular health framework centered on prevention. This framework includes primordial prevention strategies [25], population-level strategies, and personalized strategies for individuals with pre-existing conditions [28]. Community-centered approaches to public health and genomic research engagement in African American populations hold promise in raising health standards among disenfranchised groups. Strategic partnerships and coalitions can serve as catalysts for sustainable change in reducing the effects of structural racism on health disparities in vulnerable target groups [2]; the Gullah Geechee peoples of the coastal SE United States represent an important group for our study of community engagement.

Who are the Gullah Geechee Peoples?

The Gullah Geechee community represents a distinct micro ethnic group within Legacy African Americans. They are the descendants of West, Central, and Southeast African ethnic and regional groups enslaved during the 16th and 17th centuries, who were transported to the lowland regions of present-day US states including North Carolina, South Carolina, Georgia, and Florida. These individuals toiled on plantations, cultivating crops such as coastal rice, Sea Island cotton, and indigo [13]. Following emancipation, many of their descendants chose to remain on their ancestral lands.

What sets the Gullah Geechee apart is the remarkable preservation of African cultural practices and apparent African-derived genetic traits when compared to their counterparts in more inland regions of these states. Their origins are deeply intertwined with the history of American Slavery, where they played a crucial role in the economic foundations of the American South. Gullah Geechee hands were responsible for producing the first rice to be exported from South Carolina. By 1808, nearly 360,000 ancestors of Legacy African Americans were enslaved, with approximately 40% (or 187,000 individuals) entering the United States through the seaport of Charleston, South Carolina, situated within the territory of the enslaved Gullah Geechee peoples. This area, the wealthiest in British North America, became an incubator for a significant branch of Legacy African American culture. Between 1783 and 1808, generations of enslaved individuals from the Windward Coast of Africa and the savannahs of West Central Africa, along with first-generation Legacy African Americans, outnumbered European residents in Charleston by a ratio of 3:1. These Diasporic Africans, numbering around 100,000, laid the foundation for Gullah Geechee culture and likely influenced the formation of other Legacy African American micro ethnic groups in the southeastern United States [6].

Due to their relative geographic isolation, the Gullah Geechee community preserved a rich traditional African cultural heritage and lifestyle, partly owing to the ecological similarities between the Low country and many regions of tropical Africa. They also developed a creole-based language with significant influences from West Africa and Europe [45]. Dr. Lorenzo Dow Turner's seminal work meticulously documented the sentence structure, grammar, words, and customs used by the Gullah Geechee, firmly establishing their traditional culture as both unique in North America and predominantly African-derived [45].

From a demographic standpoint, enslaved Africans and enslaved and freed Legacy African Americans in the Carolina Coast regions maintained high reproductive rates, resulting in over 250,000 modern descendants [26, 42]. This reproductive pattern contributed to the Gullah Geechee and affiliated groups becoming a dominant force, potentially influencing general Legacy African American culture, migration patterns, ancestry, and subtly but profoundly shaping the larger American landscape.

Community Engagement Strategies

Against this historical backdrop, our community engagement strategies were implemented to investigate both ancestral and environmental factors contributing to cardiovascular disease among the Gullah

Geechee descendants. We conducted extensive literature reviews to inform our Project SuGAR, which laid the foundation for understanding cardiovascular disease trends in Gullah Geechee communities in South Carolina. Additionally, the Sea Islands Genetic African American Registry Project represented the first cross-sectional analysis specifically targeting the Gullah Geechee to assess the genetic basis, prevalence, and complications associated with Type 2 diabetes within their community.

Legacy African Americans typically exhibit greater insulin resistance, hypertension, and a distinct lipid profile when compared to their European American counterparts [38]. The SuGAR study reported high levels of cardio metabolic risk factors and prominent vascular disease in participants with self-reported diagnoses of type 2 diabetes. However, it did not establish a causal mechanism. Our research findings indicated that by including the Gullah Geechee in genomic-based analyses of Legacy African Americans, we can collect more insightful data to reconstruct ancestral differences contributing to the diversity observed in the broader Legacy African American population [16].

In contrast, our community-centered protocol focuses on the analysis of contemporary Gullah Geechee communities. We posit that the earliest Gullah Geechee groups served as progenitors for more recent Legacy African American communities and may harbor many of the most salient genetic and biocultural factors influencing their propensity for cardiovascular disease. Consequently, current Gullah Geechee populations serve as an ideal case study capable of generating insights valuable to a broad spectrum of African American communities [6].

Here, we present a comprehensive protocol for optimizing public health and community engagement strategies based on data collected from the Gullah Geechee. These strategies have the potential to be beneficial for numerous African American communities and other communities of people of color in promoting genomic testing and population-based solutions to cardiovascular disease. In this community engagement study, our specific target population is the Gullah Geechee community of Charleston, South Carolina.

A Community Engagement Case Study

In the context of the Gullah Geechee community, numerous governing institutions play pivotal roles. Academic scholars, grassroots organizations, and entities such as the Gullah Geechee Cultural Heritage Corridor Commissioners form part of Charleston's leadership hierarchy. Within this system, elders hold significant authority, and women often occupy more leadership positions than men, possibly reflecting cultural retentions from West African matriarchal societies—many of which were major sources of enslaved Africans for North America.

In community engagement methods, word of mouth functions as an effective public relations strategy, but it is often preceded by a reputation for goodwill. Our research has firmly established that the Gullah Geechee community has suffered substantial land loss due to external forces, primarily driven by eminent domain, gentrification, and resort development. Addressing this perception of vulnerability to exploitation is a crucial prerequisite for meaningful community engagement. Early recognition of these sensitivities enabled us to navigate the Gullah Geechee ecosystem effectively. Building relationships with

the governing institutions, assessing their needs from a community perspective, supporting local businesses, participating in community events, asking pertinent questions, and allowing the community to contribute value to the project are all essential steps.

Charleston has undergone significant transformations in the last 80 years, as have the lifestyle habits of the Gullah Geechee. Some individuals within the community now describe their language as a "hybrid." This transformation is attributed to reduced isolation, increased interactions with various groups, frequent travel, and exposure to different academic circles, which have influenced the evolution of the Gullah Geechee language. Additionally, while residing in the heart of Gullah Geechee territory, some Charlestonians may not be fully accepted as genuine Gullah Geechee. Distinguishing who is considered authentic and understanding the criteria for this status is crucial for successful research. These observations hold particular importance within a micro ethnic group like the Gullah Geechee, as an individual's value system is shaped by the culture they absorb [44] and prioritize.

In African American communities, including Gullah Geechee communities, institutions such as the church, grassroots organizations, academic entities, and local government all contribute to the current cultural climate. As Andrew Billingsley and his colleagues note, "there are three basic institutions in the African-American community: The Church, the Family, and the school" [3]. Among these, the church and family play central roles. In Gullah Geechee communities, the church holds a unique place in family lineage. It preserves cultural memories and historical traditions, with many families being connected to churches founded or built by their forefathers during enslavement.

An exemplary illustration of the strong bond between church and family lineage is St. James United Presbyterian on James Island seen in Figure 2. Following a fire that destroyed the St. James Island Presbyterian church, where the Gullah Geechee worshiped alongside the plantation owners, the Gullah Geechee congregation rebuilt their church, retaining the same name as their counterparts who worshiped nearby, beside an ancient oak tree. This decision held cultural significance, as large oak trees symbolize survival, power, hospitality, and safety—much like the baobab tree in many West African cultures. It mirrors the role of the church in the Gullah Geechee community, historically serving as a sanctuary during times of uncertainty. This trend still resonates in many African American families today, as the church remains a source of strength, stability, and social support [3].

Despite the Gullah Geechee's labor for European American plantation owners, many of their churches maintain distinct ethnic identities. Some churches on the Sea Islands even had segregated seating for enslaved Gullah Geechee, even when they attended the same congregation as European American owners. This suggests that while there was continuity in church services, the Gullah Geechee maintained separation and a degree of autonomy (Figure 1).



Figure 1: Seafood plays a significant role in the Gullah Geechee Heritage Corridor, serving as both a food source and a cultural resource. Crab Cracks, like the one pictured here, are common community gathering spaces. This particular crab crack event was organized by The Geechee Experience co-founders Akua Page (left) and Chris Cato (right). Researcher Jennifer Caldwell (center) actively participated in the event to gain a deeper understanding of their cultural experiences (Community Photo). Local chefs prepare food, while the community gathers inside to listen to updates and discuss concerns. Entrepreneurs, artists, musicians, and elders all contribute to cultural retention and the community experience.

Methods for Effective Community Engagement

Within our target population, specific techniques were used to produce significant community engagement in our research project. (Table 1) is a composite protocol of the guiding research goals and strategies we employed for entering and engaging the Gullah Geechee community of Charleston, SC.

Biomedical Researcher Goals	Goals with the Gullah Geechee Commznity	Strategies employed to realize the goals	References Consulted
Conduct a comprehensive review of the existing literature	Understand who comprises the community and how they perceive themselves	Obtain Academic approval for research, gain insights into academic and mainstream/ Gullah Geechee community perspectives	23,24
Identify the natural stratification within the group	Understand the different subsets within the target community	Visit different target community centers/ organizations. Become engaged in their projects and activities	22
Identify the priorities of the community, establish rapport with key community representatives, provide evidence of your intentions, address the aspirations of the group, gain their trust	Gaining trust allows researcher to gather more information	Be transparent. and personable. Be realistic and only promise what you can deliver.	12, 23,37
Method/ Study Goals			
Find Reliable Informants	Find informants that are familiar with the local culture and Gullah Geechee community organizations.	Good informants should have extensive knowledge of history, culture, and community personalities. They will instruct you on how to present yourself within the community.	39
Localize Families based upon existing population substructure	Map out neighborhoods and boroughs.	Find families creates trust within the family and community.	22,27,29
Engage in Active Participation with the Gullah Geechee community	Participate in the community way of life.	Participate in their cultural events and gain understanding of their belief systems.	33
Community Goals			
Establish Community Partners	Find community liaisons.	Find community partners in various positions in the community to get a well-rounded-perspective.	3,39

Meet the Community Where They Are	Establish comfortability with the researchers within the community.	Researchers meet participants in settings that they feel most comfortable.	39
Get Different Perspectives from within and outside the community	Allow the community to share their perspectives.	Communities are often aware of their differences. Getting diverse perspectives allows them to have options and create solutions to community problems.	42

Table 1: Community Engagement Protocol goals and strategies.

Researcher Goals

1. Develop comprehensive literature review

To effectively engage with the Gullah Geechee community, it is essential to conduct a comprehensive literature review. This review serves multiple purposes, including gaining insights into who the community is and how they perceive themselves. Educational materials should encompass theories, histories, and prior genetic research findings relevant to the community. It's crucial to explore critical perspectives that touch on community rules, values, ideals, folktales, and myths that reflect their core beliefs and practices. Additionally, historical records and temporal information should be gathered to understand the sociocultural impacts of past decisions and regulations within the community.

In the context of genomics research, cultural influences can significantly affect reproduction and health outcomes. Therefore, comprehending community beliefs about ancestry provides researchers with a unique lens through which to view their reality. A solid grasp of cultural norms also enables researchers to conduct more insightful analyses of empirical data. The literature review should encompass academic writings, popular videos, social media posts, and informal conversations regarding Gullah Geechee lineage and culture. A particular emphasis should be placed on storytelling, a tradition within the Gullah Geechee community that captures their ideas, beliefs, and some truths. This approach, combining emic and etic perspectives, allows for a more open-minded interaction with the community, fostering culturally sensitive research that offers valuable learning opportunities for both researchers and the community. Qualitative analysis, crucial for health disparities research, helps elucidate the environmental factors contributing to complex chronic diseases [22-23,44]. From these reviews, the research team can identify key aspects of Gullah Geechee ancestry and confirm their self-identity.

2. Stratify the target population groups

Understanding the diverse subsets within the Gullah Geechee community is essential at this stage. Visits to various community centers and organizations can provide insights into the issues they want to address. Researchers should actively consider the fragments within the community and investigate why the community may have reservations or opposition toward certain groups. By engaging with multiple

community organizations, the research team can gain a clearer understanding of the community's dynamics and interactions. This process of identifying substructure within the target population should also delve into understanding the reasons behind community segregation or the existence of different hierarchical levels.

3. Define the most useful data categories

Given the research focus on genomics and health disparities, it is crucial to identify the most pertinent data categories. This involves capturing the community's varying access to quality healthcare, which is known to be influenced by segregation and impacts cardiovascular health status [22, 27, 29]. This objective holds particular relevance due to the documented high rates of poor cardiovascular health within the "Stroke Belt" region. By focusing on cardiovascular-related data, the research team can derive actionable preventive measures that may be unique to the Gullah Geechee population.

4. Gain the trust of the target community

Building trust with the target community is a fundamental aspect of successful engagement. Trust allows researchers to overcome communication barriers and gather more information from participants. Transparency plays a crucial role in this process, as it eliminates the inherent apprehension often found in groups that have endured prolonged disenfranchisement and oppression. Being explicit about intentions and the protocol framework helps reduce initial ambiguity and skepticism within the target population.

Trust is nurtured over time through regular contact and consistent communication. Responding to the questions and concerns of the community demonstrates a commitment to their needs and strengthens the research's comprehensiveness. Researchers should show they have conducted thorough due diligence and possess some level of prior knowledge about the community. They should also be open to learning from the participants and seek to understand the community from as close to an emic perspective as possible, moving beyond purely academic knowledge. Building trust involves demonstrating a genuine willingness to engage with the community on a deeper level.

Identify the Study Goals

1. Find key informant(s)

In the context of Gullah Geechee research, identifying key informants is a critical initial goal. While academic literature suggests that some informants can be nominated or presented to outsiders, the research team in this case received a volunteer. It was essential to ensure that the chosen key informant was perceived as socially and politically neutral by the Gullah Geechee community. Neutrality is vital as community informants must remain objective about various perspectives within the community. A reliable informant can provide contextual information to help neutralize biases, offering insights into the community's hierarchical structure, divisions, and expectations of different stratified groups [39]. While population-based research often requires multiple informants, having one primary informant can help the research team strategize communication with different subsets of the community.

2. Localize families and familial lineages for study

Anthropological fieldwork in this research design aims to gain a detailed understanding of mating practices within the Gullah Geechee community through demographics. For instance, the research team observed that many Gullah Geechee descendants on James Island, South Carolina, had been there for generations and traditionally avoided mating with individuals less than seven generations related to them. This practice aimed to minimize the risks associated with inbreeding. The Sea Islands, where Gullah Geechee communities are concentrated, have contributed to the retention of African cultural elements among the Gullah Geechee but have also exacerbated economic disparities due to segregation, resulting in lower socio-economic mobility, limited access to healthcare, food deserts, and higher morbidity and mortality related to cardiovascular disease phenotypes [21,27,29,38]. Identifying and localizing families at various observation levels helped the research team understand the sources and levels of genetic admixture and cultural assimilation in the community and the impact of social determinants on cardiovascular health [see table 1]. Figure 2 above shows members of the Gullah Geechee community at First Presbyterian Church playing around the may pole.



Figure 2: above shows members of the Gullah Geechee community at First Presbyterian Church playing around the may pole.

3. Engage in active participation in the target community

Active participation in the target community is essential for this research methodology, drawing inspiration from Dr. Karen McCarthy Brown's holistic approach outlined in "Mama Lola: A Vodou Priestess in Brooklyn" (2001). This approach involves immersing researchers in the community's cultural context. Researchers achieved this by taking historical tours in the community, visiting cultural landmarks such as the Penn Center on St. Helena Island, exploring the home and workspace of the renowned Gullah Geechee blacksmith Mr. Phillip Simmons, and attending historic events like the original Memorial Day Celebration in Charleston. These experiences provided firsthand insights into what holds significance within the Gullah Geechee community. Active participation in community-organized events allows for a holistic interpretation of the community and adds balance to other anthropological techniques, such as engaging community informants and reviewing existing ethnographic accounts.

Identify the Community Goals

1. Establish community partners to work with

Building partnerships with the Gullah Geechee community is a crucial step in successful community engagement. Collaborating with community liaisons engenders trust and positions the research team as an honest broker within the target community. Understanding and supporting the community's goals is a significant aspect of effective engagement. Prior research has indicated an increase in research participation among Legacy African Americans when facilitated by other Legacy African Americans, including during the consent process [43]. Additionally, community partnerships create opportunities for interventions [40].

2. Meet people where they are

An effective strategy for community engagement is to engage with the Gullah Geechee community on their own terms. This involves being flexible enough to attend community events and gatherings arranged by community liaisons or informants. This approach demonstrates dedication to both the research and the community's goals. It facilitates organic conversations that provide insights into the role of language, culture, and community lifestyle habits. Collaborating with the community allows for the discovery of common objectives that align with the research team's goals. Maintaining positive relationships with the community makes it easier to re-enter the community for follow-up discussions and continued sample collection.

Discussion

How history contributes to future studies: ethnic prejudices create barriers in research

The discussion section delves into the historical context and challenges that underlie the engagement of diverse populations, particularly Legacy African Americans like the Gullah Geechee, in public health and genomic research. The COVID-19 pandemic, coupled with calls for social justice, has highlighted the need for public health to be more sensitive to the needs of Legacy African Americans and communities of color. This has shed light on the historical inequities and mistreatment experienced by these communities in the United States' healthcare system. This historical context serves as a foundation for understanding the

barriers and mistrust that exist between Legacy African American communities and the biomedical and scientific research fields.

The mistrust and abuse of Legacy African Americans in the name of biomedicine and scientific research have deep historical roots that predate their enslavement and continue to affect them today. This history includes instances of painful medical experimentation, such as Dr. Marion J. Sims' work on Legacy African American women during the era of enslavement, as well as the infamous Tuskegee Experiment, which intentionally withheld treatment from Legacy African American men with syphilis in rural Alabama. These historical events have contributed to a pervasive skepticism about biomedicine and its affiliated disciplines within the Legacy African American community, and this distrust has been passed down through generations. Additionally, disparities in medical malpractice and higher rates of medically related afflictions in ethnic minority communities compared to European American communities have further fueled this distrust.

The legacy of this distrust has implications for Legacy African American hesitancy to engage in genomic testing, resulting in their underrepresentation in essential genomic reference databases. While medical research practices have improved significantly in terms of ethics and safety, the belief that the medical system is not an advocate for this population remains deeply ingrained. Effective community engagement is seen as a crucial first step in bridging the gap between vulnerable populations and the healthcare establishment they economically support.

Presumptions about ethnicity and racial classification are another challenge in engaging diverse populations. The concept of "biological race" in biomedicine often focuses on a limited number of shared variables while ignoring the vast within-group differences. This approach fails to recognize the significant within-group variability that exists among Legacy African Americans and other communities of color. Therefore, researchers must consider the uniqueness of each subgroup's identity within the broader racial classification of "Black." This requires precision and forethought in research engagement strategies, emphasizing the reconstruction of historical and ancestral links to understand each subgroup's distinct identity.

The discussion also highlights the need for a comprehensive and culturally sensitive approach to engage with diverse and highly variable populations like the Gullah Geechee. It emphasizes the importance of understanding a community's historical past in the context of its present life in the United States. Achieving this understanding involves considering the community's mistrust of biomedical research and addressing presumptions about ethnicity and racial classification. The goal is to promote precision in engagement strategies and develop a nuanced understanding of the community's culture, environment, and genomic characteristics.

The protocol presented in the study serves as a model for engaging with the Gullah Geechee community and can be applied to facilitate genomic testing in other Legacy African American communities in future studies. It highlights the significance of building reciprocal relationships with local community partners, maintaining transparency throughout the research process, and listening to the community's desires regarding research outcomes. The authors emphasize that public health should prioritize diversity and

inclusion in research design, and community engagement strategies should play a central role in achieving this goal. Ultimately, by delving deep into the communities they serve, public health professionals can develop protocols and practices that improve the well-being of all communities and address specific vulnerabilities in particular groups.

References

- 1. https://www.cdc.gov/media/dpk/healthy-living/african-american-health/index.html.
- 2. https://www.atsdr.cdc.gov/toxguides/toxguide-22.pdf
- 3. Acevedo-Garcia D, Lochner KA, Osypuk TL, Subramanian SV. (2003) Future directions in residential segregation and health research: A multilevel approach. *Am J Public Health*. 93(2):215-21
- 4. Billingsley A, Caldwell C. (1991) The Church, the Family, and the School in the African-American Community. JNE. 60(3):427–40.
- 5. Brandt AM. (1978) Racism and research: the case of the Tuskegee Syphilis Study. Hastings Cent Rep. 8(6):21-29.
- 6. Caldwell J. Jackson F. (2021) Evolutionary Perspectives on African North American genetic diversity: origins and prospects for future investigations. Evol Anthropol. 30(4):242-52.
- 7. Carnethon M, Pu J, Howard G, Albert M, Anderson C, et al. (2017) Cardiovascular Health in African Americans: A Scientific Statement From the American Heart Association. *Circulation*. 136(21):e393-23
- 8. Corbie-Smith G, Thomas S, Williams M, Moody-Ayers S. (1999) Attitudes and beliefs of African Americans toward participation in medical research. *J Gen Intern Med.* 14(9):537-46.
- 9. Cullen W, Gulati G, Kelly B. (2020) Mental health in the COVID-19 pandemic. QJM. 113(5):311-12.
- 10. David R, Collins J. (2007) Disparities in Infant Mortality: What's Genetics Got to Do With It?. *Am J Public Health*. *97*(7):1191-97.
- 11. Divers J, Sale M, Lu L, Chen W, Lok K, et al. (2010) The genetic architecture of lipoprotein subclasses in Gullah-speaking African American families enriched for type 2 diabetes: The Sea Islands Genetic African American Registry (Project SuGAR). *J Lipid Res.* 51(3):586-97.
- 12. Earl CE, Penney PJ. (2001) The significance of trust in the research consent process with African Americans. West J Nurs Res. 23(7):753-62.
- 13. https://www.pbs.org/wnet/african-americans-many-rivers-to-cross/history/on-african-american-migrations/.
- 14. Golemon L. (2019) Medical Overtesting and Racial Distrust. Kennedy Inst Ethics J. 29(3):273–303.
- 15. Howerton M, Gibbons M, Baffi C, Gary T, Lai G, et al. (2007) Provider roles in the recruitment of underrepresented populations to cancer clinical trials. *Cancer*. 109(3):465-76.
- 16. Hunt K, Kistner-Griffin E, Spruill I, Teklehaimanot A, Garvey W, et al. (2014) Cardiovascular Risk in Gullah African Americans with High Familial Risk of Type 2 Diabetes Mellitus: Project SuGAR. *Southern Med J. 107*(10):607-14.
- 17. Jackson FLC. (2008) Ethnogenetic layering (EL): an alternative to the traditional race model in human variation and health disparity studies. *Ann Hum Biol.* 35(2):121-44.
- 18. Jackson F, Jackson L, Jackson Z. (2018) Developmental Stage Epigenetic Modifications and Clinical Symptoms Associated with the Trauma and Stress of Enslavement and Institutionalized Racism. *J Clin Epigen.* 04(02).
- 19. Jackson L, Jackson F. (2018) Intergenerational Resilience in Response to the Stress and Trauma of Enslavement and Chronic Exposure to Institutionalized Racism. *J Clin Epigen*. 4(3).
- 20. Jones C. (2002) The impact of racism on health. Ethnicity and Disease. 12(1):10-13.
- 21. Kershaw KN, Albrecht SS, Carnethon MR. (2013) Racial and ethnic residential segregation, the neighborhood socioeconomic environment, and obesity among Blacks and Mexican Americans. Am J Epidemiol. 177(4):299-309.
- 22. Kershaw KN, Diez Roux AV, Burgard SA, Lisabeth LD, Mujahid MS, et al. (2011) Metropolitan-level racial residential segregation and black-white disparities in hypertension. Am J Epidemiol. 174(5):537-45.
- 23. Kershaw T. (1990) The emerging paradigm in Black studies. In: Anderson T, ed. Washington State University Press. 4(3):17–24.

- 24. Kershaw T. (2014) Afrocentrism and the Afrocentric method. In: Afrocentric Visions: Studies in Culture and Communication. SAGE Publications. 27-44.
- 25. https://www.ncbi.nlm.nih.gov/books/NBK537222/
- 26. https://doi.org/10.1075/jpcl.24.2.13kle
- 27. Kramer M, Hogue C. (2009) Is Segregation Bad for Your Health?. Epidemiologic Rev. 31(1):178-94.
- 28. Lloyd-Jones D, Hong Y, Labarthe D, Mozaffarian D, Appel L, et al. (2010) Defining and Setting National Goals for Cardiovascular Health Promotion and Disease Reduction. *Circulation*. 121(4):586-13.
- 29. Massey DS, Fischer MJ. (2000) How segregation concentrates poverty. Ethn Racial Stud. 23(4):670-91.
- 30. Mayberry M, Mayberry J. (2002) Consent with understanding: a movement towards informed decisions. *Clin Med*. 2(6):523-26.
- 31. McGue M, Gottesman I. (1989) Genetic Linkage in Schizophrenia: Perspectives From Genetic Epidemiology. *Schizophr Bull.* 15(3):453-64.
- 32. Morris MW, Leung K, Ames D, Lickel B. (1999) Views from inside and outside: Integrating emic and etic insights about culture and justice judgment. Acad Manage Rev. 24(4):781-96.
- 33. Neitz M, Brown K. (1992) Mama Lola: A Vodou Priestess in Brooklyn. Contemporary Sociology. 21(5):720.
- 34. www.minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=61.
- 35. Powers W, Derdeyn C, Biller J, Coffey C, Hoh B, et al. (2015) 2015 American Heart Association/American Stroke Association Focused Update of the 2013 Guidelines for the Early Management of Patients With Acute Ischemic Stroke Regarding Endovascular Treatment. *Stroke*. 46(10):3020-35.
- 36. Roberts DF, Mourant AE, Kopec AC, Domaniewska-Sobczak K. (1976) The distribution of the human blood groups and other polymorphisms. Man (Lond). 11(4):597.
- 37. Ruiz DM. (1997) The Four Agreements. Philosphers Notes.
- 38. Sale MM, Garvey WT, Divers J, Spruill IJ, Langefeld CD, et al. (2009) The genetic architecture of lipoprotein subclasses in Gullah-speaking African American families enriched for type 2 diabetes: The Sea Islands Genetic African American Registry (Project SuGAR). *J Lipid Res.* 51(3):586-97.
- 39. Seidler J. (1974) On using informants: A technique for collecting quantitative data and controlling measurement error in organization analysis. Am Sociol Rev. 39(6):816-31.
- 40. Smith MR, Sharma R, Grimes D. (2014) Reducing infant mortality in Arkansas: a grassroots initiative utilizing African-American sororities. *J Ark Med Soc.* 110(10):204-5.
- 41. https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy database/2021/01/13/structural-racism-is-a-public-health-crisis.
- 42. http://theheartattackandstrokepreventioncenter.com/wp-
- 43. Taylor HA, Henderson F, Abbasi A, Clifford G. (2018) cardiovascular disease in African Americans: Innovative Community Engagement for Research Recruitment and Impact. *Am J Kidney Dis.* 72(5 Suppl 1):S43-S46.
- 44. Tillman L. (2002) Culturally Sensitive Research Approaches: An African-American Perspective. *Educ Res.* 31(9):3-12.
- 45. https://uscpress.com/Africanisms-in-the-Gullah-Dialect
- 46. https://www.penguinrandomhouse.com/books/185986/medical-apartheid-by-harriet-a-washington/
- 47. https://www.boards.ie/vbulletin/showthread.php?t=2058166010.
- 48. Yancy CW. (2020) COVID-19 and African Americans. JAMA. 323(19):1891-92.