

Exploring African American community perspectives about genomic medicine research: A literature review

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Abstract

Genomic medicine research is an important topic in the African American health care community. African American nurses and advance practice nursing professionals are poised to encourage and educate themselves and their communities about the importance of diversity in genomic medicine research. The Southern Nevada Black Nurses Association, a chapter within the larger National Black Nurses Association's, recently engaged in the National Institutes of Health *All of Us* research program to educate their members about formularies and other treatment modalities that could clinically benefit African-Americans and other populations of color. During this event, the Southern Nevada Black Nurses Association discovered that National Black Nurses Association members held ethical, legal, and social concerns about engaging in genomic medicine research that align with respective concerns reported in the literature. In this review, we discuss National Black Nurses Association concerns and how they relate to qualitative themes emerging from the literature and a recent National Academies of Science, Engineering, and Medicine event on disparities in access to genomic medicine. We conclude that researchers should engage with African American health community leaders to effectively engage the African American community in genomic medicine research and help ensure that genomic medicine does not exacerbate existing health disparities.

Keywords

Genomics, cultural diversity, African Americans, disparities, nurses, community health

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Introduction

African American nurses are valued caregivers, advocates, liaisons, and bridges between physicians and patients. African American nurse practitioners, being advance practice nursing professionals, have an extended role in patient-centered care, as they write prescriptions, develop short-term and long-term care plans to manage acute and chronic illnesses, respectively, and collaborate with physicians and other clinicians to ensure that patient needs and concerns are respectively met and addressed. As health care practitioners, researchers, and educators, African American nursing professionals engage diverse audiences in various settings (e.g. clinics, schools, places of worship) to educate and engage community members about key and important topics in medicine. Important community health topics have included, but are not limited to health care quality, efficiency, and safety; the provisioning of health care services; population health management; and informed consent in clinical research.^{1–4}

Genomic medicine research is an important consideration for the African American community because genetics and ancestry can provide scientific clues about responses to certain medications in African Americans. As a key example, the underrepresentation of African Americans in genomic medicine research has led to a poor understanding of the effectiveness of genetic-based interventions in diverse African American populations.⁵ It has also led to a seeming under-recognition and underdiagnosis of fatal genetic

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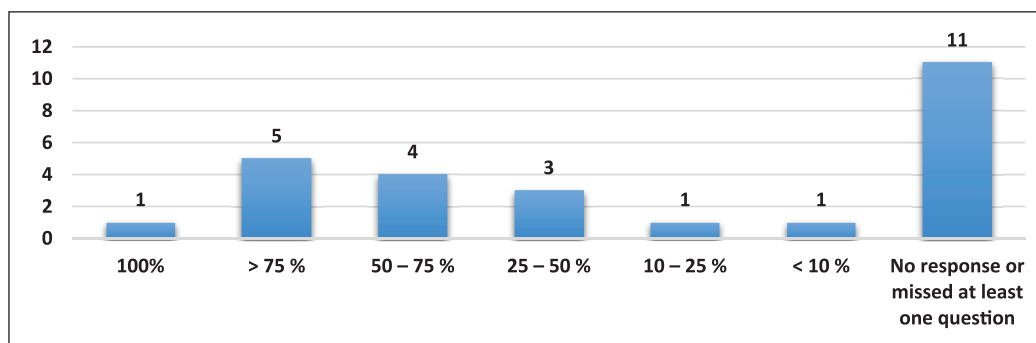


Figure 1. Number of SNBNA members interested in participating in the NIH *All of Us* program.

conditions that disproportionately affect African Americans, like transthyretin (TTR)-related hereditary cardiac amyloidosis, a genetic disease that warrants treatment with tafamidis, a pharmacogenomic drug that is Food and Drug Administration (FDA)-indicated for the TTR biomarker.^{6,7}

African American nurses are poised to educate themselves and their communities about how African American community engagement in genomic medicine research can prevent the exacerbation of current health disparities. Importantly, African American nursing professionals want to know more about the importance of African American community engagement in genomic medicine, as witnessed through the National Black Nurses Association's (NBNA)⁸ engagement in the National Institutes of Health (NIH) *All of Us* research program. The *All of Us* program was created and launched by the NIH as a key element of the nation's Precision Medicine Initiative to "extend precision medicine to all diseases by building a national research cohort of one million or more U.S. participants."⁹ In 2018, several NBNA chapters, including the Southern Nevada Black Nurses Association (SNBNA), hosted several forums to educate NBNA members about the goals of the *All of Us* research program. Presentation topics during these events were on medicines and other treatment modalities that could clinically benefit African-Americans and other populations of color.⁸ In a post-forum evaluation, the SNBNA identified several ethical, legal, and social issues and concerns about genomic research among their membership base.⁸

In this review, we describe SNBNA member perspectives or concerns about engaging in genomic medicine research. We then describe how these perspectives align with key qualitative themes described in the literature and themes reflective of key remarks made during a recent and relevant convening hosted by the National Academies of Sciences, Engineering, and Medicine (NASEM).¹⁰ We rely on these findings to substantiate the need for qualitative interviews with NBNA leaders to identify potentially new concerns that might not fit within previously identified themes, more closely assess known concerns, and determine strategies to overcome NBNA member concerns about African American community engagement in genomic medicine research. Our

summary of the literature will help to identify a model effort to identify and address relevant concerns that are possibly held by members of cultural or ethnic communities.

SNBNA member concerns about engaging in genomic medicine research

The SNBNA hosted an *All of Us* program event in 2018 and recorded questions, comments, and concerns among their members about genomic research. The SNBNA also conducted a survey to assess their members' interests in the *All of Us* program.⁸ The survey questions and qualitative analysis materials were directly provided to the NBNA by the *All of Us* program. The SNBNA reported that among 26 survey respondents (45 invited (58% response rate); see results in Figure 1), one respondent was concerned about the premise of individualized care and confused about what *All of Us* research seeks to accomplish. Several respondents (11/26) failed to fully complete the survey, resulting in only 15 completed survey responses.⁸

One survey respondent elected to participate in the *All of Us* research program upon learning about the program during an SNBNA event. However, more than half of respondents (9/15) held less than 75% interest in the program.⁸ Qualitative feedback was received, and Table 1 shows how the SNBNA member perspectives, which reflect member concerns, align with the emergent qualitative themes identified by Underwood et al., Coleman et al., and Spruill et al.⁸

Alignment of SNBNA member perspectives with key emergent themes from the literature and recent NASEM events

Themes from the literature

Qualitative themes have emerged in recent years to describe African American concerns about genomic medicine research. In particular, Underwood et al.,¹¹ Coleman et al.,¹² and Spruill et al.¹³ published such work in the *Journal of the NBNA*. Underwood et al.¹¹ identified and assessed, via

Table 1. Alignment of Southern Nevada Black Nurses Association (SNBNA) member perspectives with emergent qualitative themes.

Themes from the literature	Themes from a recent NASEM event	SNBNA member perspectives
Health-related disparities	Addressing disparities by engaging with communities to improve access to care	How will precision medicine research address health care disparities?
Historical injustices in medical research Distrust Discrimination The promise of genetic and genomic research	Historical abuse and injustice Upholding patient autonomy and protection Building trust and guidelines	Provide more information on the security of private health information to ensure breach prevention I have concerns about physician willingness to participate in <i>All of Us</i> research What are the costs of the <i>All of Us</i> program to patients? Are patients reimbursed for those costs? What is the length/duration of the <i>All of Us</i> program?
Genetics/genomic research engagement The need for genetic and genomic education Cultural competency in care interactions The role of the NBNA in providing education	Community-based collaboration Adult education on genetics and probabilistic decision making	Why are only English and Spanish versions of the <i>All of Us</i> offered? There are more languages in the United States or within National Black Nurse Association (NBNA) member communities What are effective ways to communicate with patients? Who are the target audiences/communities? How the <i>All of Us</i> program promoted to prospective participant groups?

NBNA: National Black Nurses Association.

semi-structured focus groups, African American community leader concerns about genomic medicine research. They discovered the following four key emergent themes: (1) health-related disparities, (2) historical injustices in medical research, (3) the promise of genetic and genomic research, and (4) genetics/genomic research engagement. They stressed the importance of conducting genetics/genomics research within the context of the community and with focused efforts to address determinants of health and health disparities. Similar conclusions were drawn based on results from a later study conducted by Coleman et al.,¹² which sought to identify African-American nurses' perspectives on factors that impede, support, and/or promote genetics and genomics knowledge in practice and through participation in research. After conducting focused discussions with six NBNA members, they found similar emergent themes: (1) the need for genetic and genomic education, (2) distrust, (3) cultural competency in care interactions, and (4) the role of the NBNA in providing education.¹² In 2009, Spruill et al.¹³ found, via a survey among 77 NBNA members, that most respondents (77.9%) believed that genetic tests could be used to discriminate against minorities. They also found that more than half (56%) of the NBNA respondents self-reported poor or fair knowledge about genetics/genomics; however, most of the respondents (93.5%) expressed interest in participating in planned genetics/genomics education.¹³

The NBNA comprised adults who are or descend from the United States, Africa, and other African diaspora regions. Therefore, it is likely that concerns among NBNA membership about participation in genomic medicine research could vary based on age and member affiliations with geographies across Africa and the African diaspora. A recent study was

conducted to determine whether ethnic identity might influence beliefs about, and intentions to learn, genomic results.¹⁴ The researchers found that among 408 healthy participants between the ages of 40 and 65 years who self-identified as African, African American, or Afro-Caribbean, two factors were significantly correlated with an intent to receive genomic testing results among study participants who held a strong ethnic identity (cognitive beliefs ($p < 0.001$) and the expectation to benefit from genomic research participation ($p < 0.002$)). A recent qualitative study involving in-depth interviews with 38 Black African adult immigrants also found that sociocultural underpinnings of African immigrants, or beliefs and customs that differ from Western conceptions of medicine and health, also serve as barriers and facilitators to African immigrant participation in genomic medicine research.¹⁵

Prior studies have sought to examine current barriers to achieving African American representation in genomic research. Poor study recruitment and retention are reported as key barriers rooted in psychosocial impacts, cultural beliefs, and other personal and historical factors.^{13,16-18} Individuals' desires to protect themselves and future generations from harm (e.g. discrimination and exploitation) were particularly prevalent among Africans who reported to have witnessed colonial mistreatment and exploitation by Western researchers working within sub-Saharan Africa.¹⁷ Buseh et al.¹⁵ explained that the keys to building trust and overcoming African Americans "trepidation and resistance" to participation in genomics-related research are (1) early and sustained engagement with the African American community, (2) partnerships with African American community stakeholders to map research priorities, (3) upholding ethical

conduct of research, and (4) guaranteeing equitable distribution of benefits achieved through genomics research.

Themes from a recent NASEM event

The NASEM recently convened workshops to discuss disparities in access to genomic medicine and assess barriers and potential strategies for underrepresented populations to overcome those barriers.¹⁰ Important ethical, legal, and social themes captured during these events include (1) community-based collaboration, (2) upholding patient autonomy and protection, (3) historical abuse and injustice, (4) increasing diversity in the clinical workforce, (5) building trust and guidelines, (6) addressing disparities by engaging with communities to improve access to care, and (7) education on genetics and probabilistic decision making. Altogether, these themes coincide with themes identified in the literature and captured among SNBNA members (see Table 1).¹⁰

During the workshop, the participants underscored the need for greater diversity among researchers and key personnel in genomics to promote the recruitment of minority populations in genomic medicine research.¹⁰ Among the participants was Dr Jacquelyn Taylor, a pediatric nurse practitioner and health equity and genomics researcher. Dr Taylor discussed the importance of implementing community-based collaboration (e.g. collaboration with historically Black organizations) as a recruitment strategy for genomic research in African and African American populations.¹⁰ Specifically, Dr Taylor stated, “Go to the community, reach out to the community and find out what they want and what they feel they need and actually provide those services in a community-based manner.”¹⁰ Dr Otis Brawley, a physician and distinguished professor, explained that the law requires researchers to “encourage” minority participation in clinical trials, which might undermine or disregard patient autonomy and the right for patients to make their own medical decisions.¹⁰ Dr Reed Tuckson, a physician, added that historical injustices like the Tuskegee syphilis study are a reminder to many African Americans about their vulnerability to abuse in scientific research and that people of color are rightfully wary of engaging in genomic testing and research that involves the sharing of genomic information.¹⁰ Dr Tuckson explained that stakeholders should clarify needed protections and how genomic research information should be used outside clinical settings.¹⁰ Regarding community-based collaboration, Dr Tuckson shared his opinion that community-based organizations and leaders are well-positioned to (1) deliver adult education on genetics and probabilistic decision making to ultimately empower communities in their quest to understand genetic risk and associated prevention measures, (2) develop better guidelines on how clinicians and researchers can build trust in the community and engage in productive conversations about genomic research, and (3) offer advice on best practices for connecting with their communities and improving access to care.¹⁰

Engaging health community leaders in genomic medicine research

African American health community leader engagement is needed to determine strategies to overcome African American community concerns about genomic medicine research and help ensure that genomic medicine does not become an avenue to further exacerbate health disparities in the African American population. Given recent findings by Turbitt et al.¹⁴ and Buseh et al.,¹⁸ future work should determine whether descriptive factors (e.g. age, immigrant status, and ethnic identity) that fall within the context of affiliation with Africa and/or African diaspora regions might influence NBNA members’ participation in genomic medicine research or serve as transnational roadblocks for delivering genomic healthcare.¹⁷ We consider such work as potentially model and adaptable effort to address unique yet long-held concerns among vulnerable members of culturally or ethnically diverse communities. Best practices and engagement strategies should be openly disseminated to support accelerated engagement among the larger African American community in genomic medicine research. Our program is necessary to promote the establishment of clinical recommendations based on genetic biomarkers found within populations that adequately represent African Americans and disseminate ethically sound practices and strategies to engage African Americans in genomic medicine research.

Authors’ Note

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