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

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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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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.

**Keywords:** Blacks, viewpoint, genomic, DNA, research, minority

**BACKGROUND**

Recruiting African Americans (AAs) and other marginalized communities into genomic-related health research is challenging and widespread, ranging from studies involving DNA sequencing to gene-drug interactions. George, Duran, & Norris (2014) attribute the primary reason for this is due to mistrust in researchers. Other studies demonstrate that AAs may be more difficult to recruit based on mistrust of the health care system, misuse of genomic data, privacy and confidentiality concerns, and awareness of unethical research practices in human experimentation, like the 1932 Tuskegee Syphilis Study (Otado et al., 2015; Sankaré et al., 2015; Spence & Oltmanns, 2011). Other factors, such as socioeconomic status and the type of intervention being studied have been reported and historically, have been shown to disproportionately affect AA participation in research compared to other communities. Participation barriers influence health disparities which may lead to missed economic opportunities and health promotion, inequalities, premature death, and reduced quality of life.

**AIMS**

This review aims to investigate participation barriers in genomic-related health research among AA research participants and other marginalized groups. Inclusion criteria was developed a priori and limited to studies that explored perceptions on genomic-related health research among AAs or persons of African descent (which included or excluded other minority ethnic groups) and examined barriers and facilitators influencing participation in health-related research involving DNA.

**METHOD**

**Protocol and Registration**

This review’s methodology was developed in accordance with guidelines outlined by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses, PRISMA (Moher et al., 2009) and studies were selected if they analyzed barriers to participation in genomic-related health research among priority populations (i.e., AA research participants and other ethnic minority populations). Searches for published articles occurred on January 6, 2019. Of the 38 results retrieved, 21 were focused exclusively on feedback from AA research participants (i.e., persons of African, African American, and African-Caribbean ancestry), 9 were focused on feedback from AA and other ethnic minority research participants (i.e., persons of Cuban, Puerto Rican, Mexican, South American, Central American, Asian, and Native American ancestry), and 8 were focused on feedback from Whites (i.e., persons from European ancestry).

**Eligibility Criteria**

The investigation focused on English language research literature published between January 2008 and
December 2018 in PubMed and Scopus. The overarching goal was to examine expressed viewpoints about genomic-related health research among AAs and other marginalized communities willing or unwilling to participate in genomic-related health research.

**Participants**

Research participants were nationals of or identified their ancestral origin as Asia, Cameroon, Canada, the Caribbean, Central Africa, Democratic Republic of the Congo, Eritrea, Europe, Gabon, Ghana, Kenya, Native American, Nigeria, Senegal, Sierra Leone, Somalia, Uganda, United Kingdom, and United States. Ethnic minority stratification was identified as African, African American, African Caribbean ancestry; mixed ethnicity as groupings of African, African American, African Caribbean, Cuban, Puerto Rican, Mexican, South American, Central American, Asian, and Native American ancestry; and other ethnic populations as any combination of European or White, African, African American, African Caribbean, Cuban, Puerto Rican, Mexican, South American, Central American, Asian, and Native American. The composition of participants were community members, patients, cancer survivors, students, donors, disease diagnosed persons, health and medical professionals, and health policymakers recruited from residential exchanges, biobanks, health systems (i.e., hospitals, outpatient clinics, transplantation centers, and academic medical centers), health education conferences, churches, college campuses, assisted living facilities and nursing homes, barber and nail salons, community-based organizations (i.e., wellness, fitness, oncology, and breast cancer support centers), health fairs, courthouses, professional associations and societies, shelters, bus stops, neighborhood parks and associations, sports venues, grocery stores, laundromats, rural townships and urban communities, gas stations, check cashing venues. Sample sizes were approximated: 9,408 AA subjects (comprising persons of African, African American, and African Caribbean ancestry) were sampled as; 5,353 White subjects (comprising persons of European ancestry) were sampled; 1,118 Hispanic subjects (comprising persons of Cuban, Puerto Rican, Mexican, South American, Central American, or other Spanish ancestry) were sampled; and 794 other ethnic populations (comprising persons of Asian and Native American ancestry) were sampled. The mean age of research participants ranged from 32.5 to 64.3 and for AAs, ranged from 33.4 to 55 years.

**Problem**

The paucity of data on AA participation in genomic-related health research is often attributed to difficulty in recruitment and retention and reasons for not participating remain unclear. This may lead to missed economic opportunities, health inequalities, poor health, reduced quality of life, and premature death.

**Quality Rating**

Quality review scores were denoted as positive or neutral (Shea, 2017). Of the included studies, 32 received a positive quality rating and the remaining 6 received neutral ratings (Bussey-Jones et al., 2010; Cottler et al., 2013; Kennedy et al., 2011; McDonald et al., 2012; McDonald et al., 2014; and Yu et al., 2013). The neutral ratings were based on misreported information of an individual’s viewpoint about their willingness to participate in genomic-related health research leading to inferences drawn by authors; incorrect reporting of sample size, income, education, and ethnic demographic data when comparing diagrammatic data to that which was reported from investigators; ambiguous descriptive data about participant responses on barriers and facilitators to participate in genomic health research; and an incomplete research study which the author attributed to recruitment issues.

**Intervention**

Only studies that included interventions towards genomic-related research involving risk for a chronic health condition were included.
Outcomes
Interventions that presented outcomes related to AA viewpoint assessments about acceptance barriers to participate in genomic-related health research among AAs (and other marginalized communities) were included.

Study Design
Qualitative, quantitative, and mixed-methods studies published between January 2008 and December 2018 were included in this review.

Information Sources
With the research team, studies were independently assessed for eligibility by two reviewers who performed the screening process independently. Titles were screened first, followed by screening of abstracts and finally full text articles were screened when appropriate. Conflicts were resolved through negotiation between the two screeners, to attain consensus. The search strategy comprised the application of the following keyword combinations and Medical Subject Heading terms: African, Black, minority, immigrant, viewpoint, attitude, genomic, research, DNA, health research, genetic, effective recruitment, participation, sociocultural influences, genetic risk, assessment, test, genotype, biobank, community leader, and genetic studies. To ensure all relevant studies were captured, bibliographies of included studies were reviewed. Inclusion of these additional studies were designated as hand search. The included studies assessed viewpoints from AAs and other minority ethnic research participants via structured in person and telephone interviews and focus groups, including adult and sibling pairs (qualitative); questionnaires and surveys (quantitative); and mixed-method approaches.

Study Selection
Two researchers independently used the PRISMA model to critically appraise each study (Moher et al., 2009). A total of 38 publications met inclusion criteria for this review. See Table 1. Studies were excluded if the study did not comprise or include African American research participants, non-English speakers and writers, or a method involving the qualitative or quantitative assessment of viewpoints about participation barriers and willingness to participate in genomic-related health research.

Data Extraction
Key data were extracted from included studies by three research team members. These data included geographical location, disease classification, and ethnic and ancestral origin. Research team members grouped disease classification into the following categories: cancer, cardiovascular disease; diabetes, DNA/blood sampling, epidemiology, genetic/genomic testing, health-related, human immunodeficiency virus (HIV), medical, and various. See Table 3. Instruments were developed to assess accuracy and validity of quantitative data available in studies and quality review scores were assigned to each study based on consistency of reported elements to aid the interpretation of data collection.

Synthesis of Results
The data extracted from the included studies were combined to present in narrative form. All authors examined the results for consensus that the data presented addressed the review’s research question: What are the barriers to acceptance of genomic-related health research among AAs and other minority populations?

RESULTS

After identifying 119 unique studies, 38 full-text articles were assessed for eligibility and met the inclusion criteria for methodological quality (see Figure 1). The studies were classified for inclusion according to PRISMA’s review elements: identification, screening, eligibility, and included studies. Each study included quantitative, qualitative, and mixed-methods approaches to collecting data. A total of 18 duplicate studies were excluded from this review.

Study Design and Purpose

The studies included in this review varied in design and purpose. Research was carried out between 1998 and 2017 and conducted in Canada, Nigeria, the United Kingdom, and the United States and assessment conducted ranged in duration from one month to five years and assessments lasted between 15 and 120 minutes. Twenty-five studies engaged qualitative methods (comprising in-person, telephonic, and focus group interviews, including adult and sibling pairs), seven studies engaged quantitative methods (comprising questionnaires and surveys), and six studies engaged mixed-methods. The purpose of the interventions examined barriers and facilitators to participate in genomic-related health research.

Qualitative Studies

The following qualitative studies were conducted to assess characteristics, participation, and perceptions about genetic health research among individuals with personal or familial history of hereditary disease and recipients of health care services, and community members: Amiri et al., 2014; Cottler et al., 2013, Edwards et al., 2008, Gill et al., 2013; Glenn et al., 2012; Goldenberg et al., 2010; Gordon et al., 2018; Henderson et al., 2008, Hurtado-de-Mendoza et al., 2009; Jenkins et al., 2009; Johnson et al. 2009; Kennedy et al., 2011; Lemke et al., 2010; McDonald et al., 2012; McDonald et al., 2012; Mezuk et al., 2008; Pettey et al., 2015; Ramirez et al., 2015; Rodgers et al., 2018; Scarinici et al., 2013; Still et al., 2014; Streicher et al., 2011; Sussner et al., 2009; Walker et al., 2014; and Yu et al., 2013.

Quantitative Studies

The following quantitative studies were conducted to assess indicators for effective recruitment, research participant’s intention or willingness to engage in biomedical research (including those involving clinical trials), and factors affecting research participation: Braunstein et al., 2008; Byrd et al., 2011; Diaz et al., 2008; Jones et al., 2017; Lang et al., 2013; McDonald et al., 2014; and Spruill et al., 2009.

Mixed-Methods Studies

The following mixed-methods studies were conducted to assess participation in genetic testing by social groupings, participation in genomics research and DNA biobanking, trust in genetic research, attitudes about genomics testing for complex diseases, and the desire to receive personal genetic results: Alford et al., 2010; Buseh et al., 2012; Bussey-Jones et al., 2010; Fagbemiro & Adebamowo, 2014; Kapiriri et al., 2017; and Sanderson et al., 2013.

Study Findings

AA participants who were interviewed expressed concerns about trust and the lack of sensitivity on part of research investigators regarding historical abuses that have occurred in AA communities, like the Tuskegee Syphilis Study; having predisposed socioeconomic influences, distrust of the healthcare system, psychosocial impacts, misuse of genomic data, privacy and confidentiality concerns, research stigmatization, employment discrimination, lacking health literacy, adverse impacts to cultural beliefs, lack of community and civic support, and perceived and/or actual past negative experiences as a research participant. The findings demonstrated There were high frequency rates across thematic areas associated with participation barriers
experienced by AAs (see Figure 3). Overall thematic frequency rates in AA-only studies yielded a 68% rate compared to mixed minority ethnic population studies at 12% and all other studies at 8%. Top-five themes: 1) researcher mistrust and historical abuses in health research; 2) psychosocial factors, including perceived and/or actual or past negative experiences involving health-related research, including depression, anxiety, social disruption and risk perceptions; 3) participation in a research study would cause harm and/or no benefit to a person’s health status, including a disease condition or overall quality of life; 4) fear of health status and/or medical diagnosis of an individual who would otherwise not have known or had an interest in wanting to know their health status, including disease condition; and 5) research stigmatization associated with health status or a disease condition labeled to a particular ethnic population group which would subject an individual to alienation and/or cause harmful consequences. Aggregate findings of results indicate that viewpoint assessments were dominant among AAs. Feedback collected from studies comprising non-AA participants (i.e., other ethnic minority populations) were closely similar to AAs regarding mistrust on part of research investigators and participant’s lack of knowledge about a research study, including risks and benefits. Other pervasive feedback included the need to address psychosocial factors (such as feelings of depression, anxiety, embarrassment, loneliness, and despair) and risk perceptions about research investigators. Participants described that research investigators were more trusting if they resembled belonging to the same ethnic population group as the participant which would make them feel more comfortable engaging with the investigator (Gill et al., 2013). Studies involving ethnic minorities and individuals who were “White, more educated, more knowledgeable about genetic research, and more trusting of medical researchers” (Henderson et al., 2008) were found to be less reluctant to participate in a genomic health study. Other concerns raised about participating in genomic-related health research were the need to ensure participants were educated about genetic research broadly through public awareness campaigns and other communicative efforts and ensure recruitment efforts were aimed towards ethnically diverse groups, including disease advocacy groups (Lenke et al., 2010). Participants also expressed the need to ensure that recruitment efforts targeting ethnic minority populations comprise educational learning opportunities that elucidate genetic research and composite information, such as genomic data sharing and genetic counseling (Lenke et al., 2010; Streicher et al., 2011; Glenn et al., 2012; Ramirez et al., 2015). In other studies, participants expressed need for investigators to incorporate community health workers into research teams which play an integral role in reducing recruitment challenges (Cottler et al., 2013). These findings emphasize the need to address concerns about recruitment challenges critically and steadfast. The top five thematic participation barriers common among all ethnic populations are: 1) researcher mistrust and historical abuses in research, 2) psychosocial impacts and risk perceptions, 3) harm or no benefit to subjects and actual or perceived negative experiences, 4) fear of knowing their health status or health condition, including medical diagnoses, and 5) research stigmatization. The major differences between populations regarding participation barrier is that AAs were more reluctant to participate due to known historical abuses in biomedical research, including clinical trials, and overall mistrust with researchers. Some studies were distinguishable:

Buseh et al. discussed that AAs feel they would be harmed as participants due to historical and colonial mistreatment of African ancestry research participants and expressed that their participation would not contribute to altruist solutions towards prevention of disease. They also indicated that they were not likely to participate because they believed their genetic data would be misused and could lead to deportation to their home countries based on undocumented immigration status. Other pervasive factors included psychosocial factors and cultural beliefs.

Byrd et al. also discussed that AAs lack trust in participating due to historical abuses in human experimentation against AAs and in some cases, their reluctance to participate was due to not having sufficient time to engage in the research study due to lack of time or being too busy, having a health issue, and not having an interest in participating.

Diaz et al. discussed that AAs were reluctant to participate due to confidentiality and privacy concerns and they believed investigators were untrustworthy.

Edwards et al. discussed that AAs were concerned about the effect participation would have on their family
and the potential of learning about a health condition that would affect their children and other family members who could be disease-gene carriers. AAs also believed that they could develop guilt after obtaining knowledge about a life-threatening health and could be singled out or viewed negatively because of this. As well, they felt that knowing they carry a life threatening genetic variant could lead to feelings of suicide. There was also concern about confidentiality and losing their health insurance coverage.

Fagbemiro et al. discussed that AAs felt their children may face psychosocial impacts derived from positive genetic findings of a life-threatening health condition and believed that participating in genomic health-related research would present harm to the fetus of their unborn offspring as well as having to face dilemmas associated with what decisions about aborting the fetus. Other viewpoints discussed religious concerns and not having access to an intervention combat disease upon a pathogenic finding.

Gordon et al. discussed that AAs had concerns about genetic variants known to have harmful effects on health conditions that could place them at risk for adverse conditions, such as kidney failure. Others expressed their fear in experiencing distress from learning about a pathogenic variant believing it could result in harm and AAs were apprehensive about participating due to concerns about health insurance discrimination and not being able to afford the cost of genetic testing. In addition, AAs expressed the belief that they are likely to be stigmatized as research participants and discriminated on based on their ethnic makeup.

Hurtado-de-Mendoza et al. discussed that AAs believed they would develop stress; for example, stress related to breast or ovarian cancer diagnosis and/or risk of developing breast or ovarian cancer. Others believed that they could not trust medical professionals and researchers.

Jones et al. discussed that AAs would not have sufficient time to participate, was afraid of learning about an unanticipated health condition, had mistrust of researchers in misusing their genetic data (such as fears of being cloned), and not being compensated for their participation.

Kapiriri et al. discussed that AAs were reluctant to participate due to cultural beliefs, lack of privacy and confidentiality of a known health condition (such as public knowledge of their HIV status), and fear of being diagnosed of an unanticipated health condition.

Kennedy et al. indicated that AAs were reluctant to participate in genomic health-related research due to their unwillingness to participate, suggesting their lack of trust in researchers and medical professionals.

Lang et al. discussed that AAs did not have sufficient time to participate, lacked trust in medical professionals and researchers, did not want to participate in research due to issues with past human experimentation, and believed they were too old to participate.

McDonald et al. (2012) discussed that cultural factors and religious beliefs presented participation barriers in addition to temporal orientation (i.e., beliefs about specific domains of time; past, present, future and the value of genetics research).

McDonald (2012) et al. discussed AAs had distrust with investigators and study sponsors, including government and pharmaceutical companies and believed that study results could be manipulated. Participation barriers were also aligned with a lack of knowledge and/or being able to obtain information or procedures involved to participate in the study (including experiencing negative side effects), concerns about exploitation, and the potential for the results of study to have a negative impact on AA communities. AAs also expressed their reluctance to participate due to the commitment of their time.

McDonald (2014) et al. discussed that AAs were concerned with privacy and data sharing, biobanking tampering, having overall mistrust in researchers, not having legal rights to obtain their genetic data (including fearing their genetic data would not be returned to them), being harmed from the research and/or being harmed from knowing about a health condition, and psychosocial impacts. AAs also expressed that they did not have time to devote to the research study or would have issues commuting to a test site.

Pettey et al. discussed that AAs were concerned with breach of their privacy, needing more information to make a decision about participating in the research study, fear of experiencing pain, having mistrust
in researchers, being unsure if their work schedule would permit them to commit time to participate, not trusting that their participation in a research study would be helpful and/or would provide a benefit, and not trusting that their genetic data would be returned to them.

Rodgers et al. discussed that AAs had a lack of understanding about the research study and namely, not understanding certain terms associated with the research study protocol or lacking health literacy. AAs also expressed having a mistrust of the healthcare system and believed their personal health information could be misused or they would not be able to seek medical care upon a research finding. Others had an unfavorable attitude towards research.

Scarinci et al. discussed that AAs were embarrassed to participate due to psychosocial impacts and were afraid of learning about a health condition, experiencing discomfort, lacking financial resources to participate, and not being having sufficient transportation to the study site.

Spruill et al. discussed that AAs believed that participating would result in research stigmatization and discrimination against other ethnic minority populations.

Still et al. discussed that AAs were concerned with the storage and use of their DNA and had mistrust in researchers.

Sussner et al. discussed that AAs lacked confidence in researchers conducting the study and believed that their participation would jeopardize their existing health insurance coverage.

They were afraid of what they may find out about their health status and feared they may experience hopelessness, despair, an emotional reaction, and not being able to handle results from their genetic findings (including feeling ashamed if they discovered a pathogenic variant). Research stigmatization concerns also caused AAs to view participation negatively and expressed concerns of guilt if family members were impacted after they learned of a pathogenic finding.

Walker et al. discussed that AAs feared that they would have to change their lifestyle if they participated. For example, having to adhere to a special diet or exercise program and they feared having to change their medication regimen. AAs also feared they would develop some form of illness or abnormality from research findings, not having sufficient time to participate in the research study (including having to take time away from their work), and not having trust in researchers based on past human experimental abuses.

**Outcomes**

The diminishing participation of AAs in genomic research and other health-related studies have led to growing concerns about health disparities, particularly among AAs and other ethnic minority populations. Lower- and middle-income level participants in AA-only studies yielded the highest rankings (see Figures 4, 5, and 6). Lower-income participants earning $45,200 were evident in Buseh et al., 2010; Edwards et al., 2008; Gordon et al., 2008; McDonald et al., 2012; McDonald et al., 2014; Pettey et al. 2015; Rodgers et al., 2015; Still et al., 2014; and Sussner et al., 2009. Income levels were adapted to model national household income guidelines of the Pew Research Center Report (Kochhar, 2018) and were classified as lower-income (representing less than $45,200), middle-income (representing $45,200-$135,600), and upper-income (representing more than $135,600). Researchers found disparities were specific to education in that research participants who were White and had a college education were more likely to participate in genomic-related health research (Henderson et al., 2008; Amiri et al., 2014; Gill et al., 2012; Lemke et al., 2010). Education and income data were grouped by populations. See Table 2. Education levels ranged from completed less than high school education to attended or completed college education. Education data illustrated in Figure 2 represents self-reported data collected during the research viewpoint assessment. Aggregate educational level data exclusively focused on AA viewpoints averaged 5% for less than high school education completed, 17% for completion of high school education, and 15% for completion of college education or higher. Aggregate educational level data across studies that focused on viewpoints from mixed ethnic minority populations averaged 6% for less than high school education completed, 17% for completion of high school education, and 15% for either attending college or completing college education.
DISCUSSION

The paucity of AA participation barriers associated with genomic health-related research is wide-ranging and could account for difficulty in both recruitment and retention in addition to health disparities. AAs may be more difficult to recruit in genomic health-related research studies due to mistrust of investigators, psychosocial impacts, and cultural beliefs. Historically, these factors have led to missed economic opportunities, inequalities, poor health, reduced quality of life, and premature death. As research continues to uncover unethical human experimentation and as governmental regulatory bodies became increasingly aware of research misconduct practices, the importance of understanding historical underpinnings of research ethics will be key to helping strengthen ethical guidelines in medical and health research practices (Tuskegee University, 2021; National Institute of Environmental Health Sciences, 2019; Office for Human Research Protections, 2016, 2017, 2019; World Medical Association, 2019). These efforts will be instrumental in reinforcing the importance of stringent regulations needed to promote basic ethical principles of research involving humans. Research participants believe that participating in genomic-related health research would impose a change in lifestyle; require time and commitment they are not willing to invest; infringe upon cultural or religious beliefs and norms; cause discomfort and/or pain during collection of biospecimens; promote insurance and employment; would result in misuse of genomic data or failure to return genomic results; family members being adversely impacted by genetic results; result in incurred financial barriers and costs; provide no benefit to health or possibly cause irreparable consequences; induce diagnoses of a life threatening health condition; would lack of support from the community; would not provide education about the research or would exacerbate health education and health literacy challenges; would not provide language translation services; would induce concerns about privacy and confidentiality in protecting health information; there would be a lack of trustworthiness among investigators; there would be a lack of interest to participate in research; would not acknowledge past unethical research practices involving human experimentation; participation would induce psychosocial factors (e.g., stress, hostility, depression, embarrassment, hopelessness, and despair); and would lead to research stigmatization, encompassing the convergence of 1) identifying and labeling differences in human beings; 2) linking labeled individual's cultural belief to unfavorable characteristics and negative stereotype constructs; 3) categorizing individuals into groups of “us” and “them” in the application of said stereotype constructs; 4) loss of status and discrimination experienced by labeled individuals; and 5) employing social, economic, political, or other influences that reinforce and translate the aforementioned processes into detrimental outcomes for labeled individuals.

LIMITATIONS

Use of the internet as this method of collecting responses may pose a hindrance to low-educated participants who may not know how to use the internet or may have limited knowledge about utility (Alford et al., 2010). Few studies grouped study demographics by highest level of education completed jointly without stratification (Alford et al., 2010; Kennedy et al., 2011; Lemke et al., 2010; Rodgers et al., 2018) which may obscure results. Some studies were developed with outcome variables that were hypothetical in nature in which researchers evaluated intent or interest to participate in current or future genomic-related health research in contrast with actual participation (Goldenberg et al., 2010; McDonald et al., 2012; McDonald et al., 2012; Braunstein et al., 2008; Henderson et al., 2008; Diaz et al., 2008). Previous studies have shown that intention to participate does not convert to actual participation (Donovan, 2000). Some study designs were cross-sectional which limits the ability for researchers to analyze response rates over a period and do not necessarily determine causal effects of participation barriers (Cottler et al., 2013; Hurtado-de-Mendoza et al., 2016) while other studies were exploratory or observational suggesting that research may not have been well researched before and may represent response rates that are not truthful or are skewed based on participants not being situated in their natural setting when being observed (Ramirez et al., 2015). All studies reporting participant socioeconomic demographics were based on unreliable self-reporting and may potentially be skewed. Some studies reported participation incentives (e.g., cash or gift) may unduly encourage research participation and generate contrasting task outcomes and unintended outcomes (Singer & Couper, 2008; Hsieh & Kocielnik, 2016; Zutlevics, 2016). One study utilized language interpreters to increase knowledge awareness among research personnel (Gill et al., 2013). One study reported that data collection was conducted
prior to the passing of the Genetic Information Nondiscrimination Act (GINA) of 2008 (Goldenberg et al., 2010) and this may have influenced participant viewpoints. One study reported that no adjustments were considered for categorical differences in disease areas which may present challenges with disambiguating inferences drawn from the data (Amiri et al., 2014). There was evidence in one study that researchers made concerted efforts to demonstrate researcher trustworthiness which may have influenced false-positive qualitative data (Bussey-Jones et al., 2010). In another study, researchers suggested recruitment biases (Bussey-Jones et al., 2010). One study attested that due to the brevity of the data collection, results may be untenable (Cottler et al., 2013). In another study, researchers expressed that some participants may not have felt empowered to provide input because other participants in the group were overly expressive or outspoken in expressing their views (Lemke et al., 2010). Sanderson et al., (2013) did not disclose to participants what genomic health research was, including describing its significance to the viewpoint assessment. In another study, researchers reported that responses to viewpoint assessments may have possible generated findings from an inherently biased sample (Bussey-Jones et al., 2010). Some studies comprised participants who had already participated in participation barrier studies which may have skewed response rates to the present study (Bussey-Jones et al., 2010; Kapiriri et al., 2017). Sample size was reported as small and not generalizable in many studies thus manifesting low statistical power in approximating the priority population (Spruill, Coleman, & Collins-McNeil, 2009; Sussner et al., 2009; McDonald et al., 2012; McDonald et al., 2012; Jenkins et al., 2009; Kennedy et al., 2011; Glenn, Chawla, & Bastani, 2012; Walker et al., 2014; Hurtado-de-Mendoza et al., 2016; Ramirez et al., 2015; 2016; Kapiriri et al., 2017).

CONCLUSION

Diminishing participation of AAs in genomic-related health research is attributed to a range of factors leading to growing concerns about health disparities and it is important to address these factors, among marginalized communities like AAs to promote better health outcomes. Researchers should develop well-defined research protocols inclusive of CBPR approaches that make clear the purpose of the study, including risks and benefits, and provide research participants with appropriate understanding of the type of research being undertaken and the value of participating.

IMPLICATIONS FOR GENOMIC RESEARCH PRACTICE

Integrating benefit-sharing models, including quality informed consent measures seems to be a substantial and economical solution to increase recruitment.

REFERENCES


48. Sanderson, S. C., Diefenbach, M. A., Zinberg, R., Horowitz, C. R., Smirnoff, M., Zweig, M., ... Richardson, L. D. (2013, October). Willingness to participate in genomics research and desire for...


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Table 1 Studies Included in the Review

<table>
<thead>
<tr>
<th>First Author, Publication Year</th>
<th>Location</th>
<th>Participation Incentive</th>
<th>Population of Interest</th>
<th>Participation Barriers</th>
<th>Participation Facilitators</th>
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<tbody>
<tr>
<td>Alford, 2010</td>
<td>Henry Ford Health System Location</td>
<td>Yes</td>
<td>All populations</td>
<td>Lack of health literacy</td>
<td>Participation incentives/free testing</td>
</tr>
<tr>
<td>Amiri, 2014</td>
<td>Henry Ford Health System</td>
<td>Yes</td>
<td>Mixed minority</td>
<td>Researcher mistrust/historical abuses in research</td>
<td>Altruism</td>
</tr>
<tr>
<td>Braunstein, 2008</td>
<td>Outpatient cardiology and general medicine clinics</td>
<td>No</td>
<td>All populations</td>
<td>Researcher mistrust/historical abuses in research</td>
<td>Health promotion/disease prevention</td>
</tr>
<tr>
<td>Buseh, 2012</td>
<td>Community</td>
<td>No</td>
<td>AA-only</td>
<td>Harm/no benefit/negative experience</td>
<td>Health promotion/disease prevention</td>
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<tr>
<th>Study</th>
<th>Location Details</th>
<th>Populations Reached</th>
<th>Concerns</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bussey-Jones, 2010</td>
<td>North Carolina Colorectal Cancer Study</td>
<td>Yes</td>
<td>All populations previously participated in a research study, Privacy/confidentiality concerns, Researcher mistrust/historical abuses in research, Discomfort/pain, Not interested in participating</td>
</tr>
<tr>
<td>Byrd, 2011</td>
<td>Public locations (churches, health education conferences, caregiver conferences, co-ed senior homes, barber/beauty shops)</td>
<td>No</td>
<td>AA-only, Researcher mistrust/historical abuses in research, No commitment/time, Fear of health status/medical diagnosis, Not interested in participating, Compensation/participation incentive</td>
</tr>
<tr>
<td>Cottler, 2013</td>
<td>Public locations (barbershops, beauty shops, parks, shelters, bus stops, community agencies, churches, neighborhood associations, health care facilities, sports venues, grocery stores, laundromats, nail salons, fitness centers, colleges, gas stations, check cashing venues, and health fairs)</td>
<td>Yes</td>
<td>Mixed minority, Fear of health status/medical diagnosis, Health promotion/disease prevention, Comfortable/adequate research setting, Foster trust with researcher/research community, Access to health/medical records, No financial barriers/cost burdens</td>
</tr>
<tr>
<td>Diaz, 2008</td>
<td>Historically Black Colleges and Universities</td>
<td>No</td>
<td>AA-only, Privacy/confidentiality concerns, Researchers ethically resemble the community, Not interested in participating</td>
</tr>
<tr>
<td>Study</td>
<td>Setting</td>
<td>AA-only</td>
<td>Family impact</td>
</tr>
<tr>
<td>---------------</td>
<td>-------------------------------------------------------------------------</td>
<td>---------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Edwards, 2008</td>
<td>Physician referral and participant initiation</td>
<td>No</td>
<td>Research stigmatization, Psychosocial factors/risk perceptions, Fear of health status/medical diagnosis, Privacy/confidentiality concerns, Health insurance discrimination</td>
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<tr>
<td>Fagbemiro, 2014</td>
<td>Nigerian residents living in the Federal Capital Territory</td>
<td>No</td>
<td>Family impact, Fear of health status/medical diagnosis, Cultural/religious beliefs, Harm/no benefit/negative experience</td>
</tr>
<tr>
<td>Gill, 2013</td>
<td>South Asian and Black African-Caribbean communities</td>
<td>No</td>
<td>Mixed minority</td>
</tr>
<tr>
<td>Glenn, 2012</td>
<td>Community-based organizations and facilities (wellness centers, oncology centers, breast cancer support centers)</td>
<td>No</td>
<td>Mixed minority</td>
</tr>
<tr>
<td>Goldenberg, 2010</td>
<td>Academic medical center and biobanks</td>
<td>No</td>
<td>All populations</td>
</tr>
<tr>
<td>Study</td>
<td>Location/Study</td>
<td>Participation</td>
<td>Ethnicity</td>
</tr>
<tr>
<td>-------------------------------</td>
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</tr>
<tr>
<td><em>Gordon, 2018</em></td>
<td>Transplantation center</td>
<td>Yes</td>
<td>AA-only</td>
</tr>
<tr>
<td><em>Henderson, 2008</em></td>
<td>North Carolina Colorectal Cancer Study</td>
<td>Yes</td>
<td>Mixed-minority</td>
</tr>
<tr>
<td><em>Hurtado-de-Mendoza, 2016</em></td>
<td>Community-based settings and hospitals</td>
<td>Yes</td>
<td>AA-only</td>
</tr>
<tr>
<td>Ref</td>
<td>Location</td>
<td>Consent</td>
<td>Population</td>
</tr>
<tr>
<td>-----------</td>
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</tr>
<tr>
<td>Jenkins, 2009</td>
<td>Community</td>
<td>Yes</td>
<td>All populations</td>
</tr>
<tr>
<td>Johnson, 2009</td>
<td>Churches</td>
<td>No</td>
<td>Mixed-minority</td>
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</table>

(continued)
<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Group</th>
<th>Participation</th>
<th>Ethnicity</th>
<th>Concerns</th>
<th>Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jones, 2017</td>
<td>Community</td>
<td>No</td>
<td>AA-only</td>
<td>No commitment/time fear of health status/medical diagnosis</td>
<td>Altruism</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td>Psychosocial factors/risk perceptions</td>
<td>Compensation/participation incentives</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Harm/no benefit/negative experience</td>
<td>Promote diversity in research</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Misuse of genomic data</td>
<td>Return of genomic results</td>
</tr>
<tr>
<td>Kapiriri, 2017</td>
<td>AA adult HIV positive mothers</td>
<td>Yes</td>
<td>AA-only</td>
<td>Cultural/religious beliefs fear of health status/medical diagnosis</td>
<td>Receive a part of future profits gained from research</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Psychosocial factors/risk perceptions</td>
<td>Acquire/increase health literacy</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Health promotion/disease prevention</td>
</tr>
<tr>
<td>Kennedy, 2011</td>
<td>East Baton Rouge Parish, Southern University and A&amp;M College, community</td>
<td>Yes</td>
<td>AA-only</td>
<td>Not interested in participating</td>
<td>Altruism</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td>Protection of civil rights/felt protected by legal system</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Biospecimens would not be misused</td>
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<tr>
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<td></td>
<td></td>
<td></td>
<td>Health promotion/disease prevention</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Would enable breast feeding despite being diagnosed with HIV</td>
</tr>
<tr>
<td><strong>Lang, 2013</strong></td>
<td>Nonclinical setting</td>
<td>No</td>
<td>AA-only</td>
<td>No commitment/time</td>
<td>Researcher mistrust/historical abuses in research</td>
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<tr>
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</tr>
<tr>
<td><strong>Lemke, 2010</strong></td>
<td>Outpatient clinics and hospitals</td>
<td>Yes</td>
<td>Mixed-minority</td>
<td>Privacy/confidentiality concerns</td>
<td>Researcher mistrust/historical research abuses</td>
</tr>
<tr>
<td><strong>McDonald, 2012</strong></td>
<td>University of Pennsylvania Hospital System</td>
<td>Yes</td>
<td>AA-only</td>
<td>Cultural/religious beliefs</td>
<td>Temporal orientation</td>
</tr>
<tr>
<td>Study</td>
<td>Type of Recruitment</td>
<td>Consent</td>
<td>Ethnicity</td>
<td>Incentives</td>
<td></td>
</tr>
<tr>
<td>---------------</td>
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<td>-----------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td><em>McDonald, 2012</em></td>
<td>Self-referrals and public locations</td>
<td>Yes</td>
<td>AA-only</td>
<td>Researcher mistrust/historical abuses in research Misuse of genomic data Lack of knowledge about study Harm/no benefit/negative experience Research stigmatization</td>
<td></td>
</tr>
<tr>
<td><em>McDonald, 2014</em></td>
<td>Residential exchanges nationwide</td>
<td>Yes</td>
<td>AA-only</td>
<td>Patients who usually received healthcare at a community health clinic or public facility were more likely to participate</td>
<td></td>
</tr>
<tr>
<td>Mezuk, 2008</td>
<td>National Institute of Mental Health Epidemiologic Catchment Area</td>
<td>Yes</td>
<td>All populations</td>
<td>Psychosocial factors</td>
<td>Altruism Health promotion/disease prevention Knowing how genomic data will be used Acquire/increase health literacy Researchers ethnically resemble the community (namely, minority communities) Family impact Compensation/participation incentive Promote diversity in research Would participate if biospecimen collected were administered via cheek swab or saliva sample versus blood draws</td>
</tr>
<tr>
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</tr>
<tr>
<td>Pettys, 2015</td>
<td>Faith-based urban clinic</td>
<td>No</td>
<td>AA-only</td>
<td>Privacy/confidential concerns Lack of knowledge about study Discomfort/pain Misuse of genomic data Researcher mistrust/historical abuses in research Harm/no benefit No return of genomic results Genomic testing would help healthcare providers manage healthcare Compensation/participation incentives Health promotion/disease prevention Promote lifestyle change</td>
<td></td>
</tr>
<tr>
<td><strong>Ramirez, 2015</strong></td>
<td>National Cancer Institute (NCI) Special Populations Networks (SPN) for Cancer Awareness, Research, and Training program and the NCI Cancer Genetics Network partnered with Susan G. Komen for the Cure</td>
<td>NR</td>
<td>Mixed-minority</td>
<td>Psychosocial factors/risk perceptions Family impact Privacy/confidentiality concerns Researcher mistrust/historical abuses in research Financial barriers/cost burdens Harm/no benefit Health insurance discrimination Lack of health literacy</td>
<td>Altruism Genomic testing would help healthcare providers Health promotion/disease prevention</td>
</tr>
<tr>
<td><strong>Rodgers, 2018</strong></td>
<td>Community Yes</td>
<td>AA-only</td>
<td>Altruism Genomic testing would help healthcare providers Health promotion/disease prevention</td>
<td></td>
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<tr>
<td><strong>Sanderson, 2013</strong></td>
<td>Inner city hospital outpatient clinic</td>
<td>No</td>
<td>All populations</td>
<td>Health promotion/disease prevention Learn about genetic testing Learn about children’s risk to disease genetic variants</td>
<td></td>
</tr>
<tr>
<td><strong>Scarinci, 2013</strong></td>
<td>Public health clinic and community</td>
<td>No</td>
<td>AA-only</td>
<td>Health promotion/disease prevention Learn about genetic testing Learn about children’s risk to disease genetic variants</td>
<td></td>
</tr>
</tbody>
</table>

For the Cure: Community Yes AA-only Lack of health literacy Researcher mistrust/historical abuses in research Misuse of genomic data Not interested in participating Health promotion/disease prevention Learn about genetic testing Learn about children’s risk to disease genetic variants

Inner city hospital outpatient clinic: No All populations Researcher mistrust/historical abuses in research Not interested in participating Harm/no benefit Fear of health status/medical diagnosis Learn about genetic testing Learn about children’s risk to disease genetic variants

Public health clinic and community: No AA-only Psychosocial factors/risk perceptions Financial barriers/cost burdens No transportation to study site Altruism Family impact Health promotion/disease prevention Learn about genetic testing Learn about children’s risk to disease genetic variants
<table>
<thead>
<tr>
<th>Study</th>
<th>Setting</th>
<th>Will Participate</th>
<th>Minority Status</th>
<th>Research Stigmatization</th>
<th>Participate If Self-Collected Biospecimen Available</th>
<th>Family Impact</th>
<th>Health Promotion/Disease Prevention</th>
<th>Acquire/Increase Health Literacy</th>
<th>Altruism</th>
<th>Privacy/Confidentiality Concerns</th>
<th>Return of Genomic Results</th>
<th>Return of Ancestral Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spruill, 2009</td>
<td>National Black Nurses Association</td>
<td>No</td>
<td>AA-only</td>
<td>Research stigmatization</td>
<td>Would participate if self-collected biospecimen available</td>
<td>Family impact</td>
<td>Acquire/Increase health literacy</td>
<td>Health promotion/disease prevention</td>
<td>Altruism</td>
<td>Privacy/confidentiality concerns</td>
<td>Return of genomic results</td>
<td>Return of ancestral results</td>
</tr>
<tr>
<td>Still, 2014</td>
<td>Public locations (churches, beauty shops, community centers)</td>
<td>Yes</td>
<td>AA-only</td>
<td>Misuse of genomic data</td>
<td>Researcher mistrust/historical abuses in research</td>
<td>Family impact</td>
<td>Acquire/Increase health literacy</td>
<td>Health promotion/disease prevention</td>
<td>Altruism</td>
<td>Privacy/confidentiality concerns</td>
<td>Return of genomic results</td>
<td>Return of ancestral results</td>
</tr>
<tr>
<td>Streicher, 2011</td>
<td>Mount Sinai Biobank at Mount Sinai Medical Center</td>
<td>Yes</td>
<td>Mixed-minority</td>
<td>Fear of health status/medical diagnosis</td>
<td>Psychosocial factors/risk perceptions</td>
<td>Family impact</td>
<td>Acquire/Increase health literacy</td>
<td>Health promotion/disease prevention</td>
<td>Altruism</td>
<td>Privacy/confidentiality concerns</td>
<td>Return of genomic results</td>
<td>Return of ancestral results</td>
</tr>
<tr>
<td>Sussner, 2009</td>
<td>Existing longitudinal study</td>
<td>No</td>
<td>AA-only</td>
<td>Privacy/confidentiality concerns</td>
<td>Health insurance discrimination</td>
<td>Researcher mistrust/historical abuses in research</td>
<td>Acquire/Increase health literacy</td>
<td>Autonomy/self-empowerment</td>
<td>Return of genomic results</td>
<td>Return of ancestral results</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walker, 2014</td>
<td>Jackson Heart Study</td>
<td>Yes</td>
<td>AA-only</td>
<td>Change in lifestyle Fear of health status/medical diagnosis</td>
<td>No commitment/time</td>
<td>Researcher mistrust/historical abuses in research</td>
<td>Acquire/Increase health literacy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>First author, Publication Year</td>
<td>Sample size (n)</td>
<td>Mean age</td>
<td>Location</td>
<td>Gender</td>
<td>African-African</td>
<td>Minority</td>
<td></td>
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</tr>
<tr>
<td>Yu, 2013</td>
<td>Pediatric clinics, community organizations, electronic flyers on Seattle area parent electronic lists</td>
<td>Yes</td>
<td>All populations</td>
<td>Researcher mistrust/historical abuses in research Psychosocial factors/risk perceptions Fear of health status/medical diagnosis No return of genomic results</td>
<td>Health promotion/disease prevention Altruism Family impact Knowledge of health status/medical diagnosis Acquire/increase health literacy Understanding health disparities in minority populations</td>
<td>N</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 2 Study Characteristics: Education and Income Demographics
Spruill, 2009  
77  54  United States  100% female  100%  0%  0%  0%  95%  = college graduate  NR

Still, 2014  
98  53  United States  100% female  100%  0%  0%  0%  9%  < high school; 40.8% = high school; 50% = some college and beyond

Streicher, 2011  
43  43  United States  91% female  47%  49%  2%  2%  NR

Sussner, 2009  
146  45.8  United States  100% female  100%  0%  0%  0%  48%  [?] HS - 98% [?] HS 67% [?]

Walker, 2014  
140  52.5  United States  NR female  100%  0%  0%  0%  52%  [?] Bachelor's degree or higher; 28% = some college; 20% = high school 56% middle income

Yu, 2013  
41  42  United States  71% female  50% NR NR NR 76%

Table 3  
Disease Area and Research Design  
Studies included in Systematic Review, No. (%)

<table>
<thead>
<tr>
<th>Research Design</th>
<th>Cancer</th>
<th>Cardiovascular</th>
<th>Diabetes</th>
<th>DNA/blood sampling</th>
<th>Epidemiology</th>
<th>Genetic/genomic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mixed-methods</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Qualitative</td>
<td>9 (24%)</td>
<td>3 (8%)</td>
<td>1 (3%)</td>
<td>4 (11%)</td>
<td>1 (3%)</td>
<td>10 (26%)</td>
</tr>
<tr>
<td>Quantitative</td>
<td>-</td>
<td>1 (3%)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>Overall</td>
<td>9 (24%)</td>
<td>4 (11%)</td>
<td>1 (3%)</td>
<td>4 (11%)</td>
<td>1 (3%)</td>
<td>13 (34%)</td>
</tr>
</tbody>
</table>

Figure 1  
Participation Barrier Themes

[CHART]  
Note. Thematic areas observed in articles included in this review stratified by populations.

Figure 2  
Community-Based Participatory Research Conceptual Model
Note. Sample community-based participatory research concept developed by University of New Mexico Health Sciences Center.