The role of race and ethnicity in views toward and participation in genetic studies and precision medicine research in the United States: A systematic review of qualitative and quantitative studies

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Abstract

Background: Racial/ethnic minority populations in the United States are consistently underrepresented in genetic research. Large-scale public participation is required to ensure discoveries from precision medicine research are applicable to everyone. To evaluate views toward and facilitators of participation among minority populations in the United States, we conducted a systematic review of literature.

Methods: Six databases were searched for articles published from 2005 to 2018 assessing minority populations’ views and/or willingness to participate in genetic research. A thematic framework was applied to extracted data to synthesize findings, and the Socio-Ecological Model was used to evaluate papers.

Results: Review of 2,229 titles and abstracts identified 27 papers (n = 8 qualitative, n = 19 quantitative). Themes included knowledge of genetics, engagement in research, facilitators and barriers to participation, and cultural considerations. Understanding of genetics was low, yet the majority of participants were willing to participate in genetic research among all populations included in the literature (range: 57%–97%). Recommendations for research included utilizing community-based participatory approaches, evaluating participants’ informational needs, incentivizing participation, and providing direct benefits (e.g., genetic test results).

Conclusion: Results could influence future study designs that incorporate all levels of the Socio-Ecological Model and better meet the needs of underrepresented groups, thereby ensuring precision medicine research findings are applicable to all.

KEYWORDS

genetic research, precision medicine research, racial/ethnic minorities, research participation strategies

1 | INTRODUCTION

The era of precision medicine is rapidly approaching, and clinical care plans that are targeted to an individual’s unique genetic and environmental information will soon be widely applied in medicine (Adams & Petersen, 2016). Extensive research efforts are ongoing to refine our understanding of the genetic mechanisms of disease, establish methods to target...
these mechanisms with cutting-edge treatments, and develop strategies to tailor each therapy to an individual’s unique genetic profile and lifestyle (Bentley, Callier, & Rotimi, 2017). In 2007, the Genomics and Personalized Medicine Act was passed by the United States Congress, and research efforts ramped up drastically in January 2015 with the implementation of the Precision Medicine Initiative by President Barack Obama (Adams & Petersen, 2016; Barlas, 2015). However, in order for this innovative movement to become commonplace in modern health care, it is important to consider the public’s understanding and acceptance of precision medicine research. Without large-scale public participation in research involving genetic testing and precision medicine practices, this new approach to medicine will not be successful.

Wide-scale public participation in precision-based research enables investigators to cultivate databases that capture genetic diversity from a broad range of populations, thereby facilitating the development of effective individualized therapies for people of all racial and ethnic backgrounds (Sirugo, Williams, & Tishkoff, 2019). However, there is a consistent underrepresentation of individuals from racial and ethnic minority groups in the United States in genetic research (Claw et al., 2018; Need & Goldstein, 2009; Popejoy & Fullerton, 2016). A 2009 analysis reported that 96% of genetic studies were conducted on populations of European descent (terminology defined by authors; Need & Goldstein, 2009). Ten years later, Sirugo et al. (2019) reported that the majority (78%) of participants included in genome-wide association studies are still White. Participation of diverse populations allows researchers to analyze population-specific sequence variation that is linked to geographic ancestry and can influence disease presentation, medication response, diagnostic accuracy, and response to therapy (Buseh, Underwood, Stevens, Townsend, & Kelber, 2012; Sirugo et al., 2019; Spratt et al., 2016). Lack of inclusion of diverse populations in genetic research will likely lead to the inability to accurately translate findings from precision medicine research from White populations, in which the research was conducted, to racial and ethnic minority populations that are underrepresented in research. This might subsequently lead to disparities in precision medicine-based clinical care for non-White communities in the United States.

Mistrust in healthcare providers and systems as a result of historical malpractices and exploitation of racial/ethnic minority groups in medicine and research is well-documented and has often been generalized as the primary prohibiting factor to participation in research among minority populations (Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; Keller, 2006; McDonald et al., 2014). It is now recognized that the reasons for lower research participation rates among individuals racial/ethnic minority groups are multifaceted and cannot be fully explained by medical mistrust (Bentley et al., 2017; Sheppard et al., 2018). Considering the multiple levels of influence in society that impact participation rates, such as those described in the Socio-Economic Model (intrapersonal, interpersonal, organizational community, and policy), might be important to understand barriers to participation beyond medical mistrust (McLeroy, Bibeau, Steckler, & Glanz, 1988; Richard, Potvin, Kishchuk, Prlic, & Green, 1995). For example, studies have reported that lack of access and awareness, fear of discrimination, concerns about privacy and misuse of information, and differences in cultural beliefs contribute to the lack of diversity in precision medicine research (Bates, Lynch, Bevan, & Condit, 2005; Diaz, Mainous, Gavin, & Wilson, 2014; Glenn, Chawla, & Bastani, 2012; Yancey, Ortega, & Kumanyika, 2006). It is imperative to assess the perspectives and attitudes of individuals from racial/ethnic minority groups in order to provide insights into study design and recruitment strategies that will assist in inclusion of these groups in precision medicine research. Increasing participation of underrepresented groups in genetic research represents a first step toward ensuring that the advancements made by precision medicine are equally beneficial to all racial and ethnic groups, not just individuals from European backgrounds.

This systematic review attempts to fill the existing gap in the literature regarding the current understanding of attitudes and perspectives of racial/ethnic minority populations toward precision medicine research. To address what is already known about the views of racial/ethnic minority populations toward genetic testing and genetic research, we conducted a systematic review of the literature to answer the major research question: How do views and attitudes toward precision medicine research differ between minority groups, including African Americans, Asian Americans, and Hispanic individuals, compared with white individuals in the general population? We aim to bolster understanding and appreciation of minority perspectives toward genetic-based research, identify areas of research that are currently lacking, and provide recommendations that can be incorporated into future precision medicine research efforts with racial/ethnic minority populations.

## 2 | METHODS

### 2.1 | Editorial policies and ethical considerations

This research did not require approval from an ethics committee.

### 2.2 | Inclusion and exclusion criteria

The protocol for this review was registered in the PROSPERO International Prospective Register of Systematic Reviews from the National Institute for Health Research, protocol number CRD42019119677. Comprehensive search strategies were developed based on the Preferred Reporting Items for
Systematic literature search

Database searches were performed on 12 July 2018 in six databases: Medline via Ovid, EMBASE via Ovid, PsycINFO via Ovid, CINAHL via EBSCO, Web of Science, and Scopus. Search language was adapted to individual database formats. The complete search strategy for Medline is shown in Appendix A. Two thousand three hundred seven citations were returned by search queries in the six databases. Search results were downloaded into EndNote citation management software for deletion of duplicates. After deduplication, 2,229 articles were loaded into Rayyan QCRI for screening.

2.4 | Manuscript selection process

The inclusion and exclusion criteria established before conducting the database searches were applied to the final search yield (n = 2,229 articles). The primary author (E.F.) used the criteria to screen all titles and abstracts in Rayyan QCRI. To ensure general agreement in the approach taken by the primary reviewer, an independent reviewer (R.E.) screened 50% of all articles before making final inclusion/exclusion decisions. Disagreements were resolved through discussion with a third reviewer (H.Z.). Of the 50% of articles that were screened by an independent reviewer, there was a 3.76% conflict rate for inclusion/exclusion decisions (42 of 1,116 articles). The majority of discrepancies between inclusion/exclusion decisions between reviewers stemmed from one of three issues: differing perspectives of whether the article was a review or an original research study; confusion regarding the population of participants; and differentiation between genetic testing versus genetic counseling. There were zero articles that the reviewers (E.F., R.E., H.Z.) were unable to agree upon during the abstraction process.

Following review of titles and abstracts, 158 publications met inclusion criteria and were assessed for eligibility. Of these publications, 124 studies were excluded because they were conducted in a clinical setting rather than a research setting (i.e., studies that performed genetic testing for clinical management purposes rather than within the context of a voluntary research study). Thirty-four publications were included for full-text review by the primary author (E.F.). Of the 34 publications that were eligible for inclusion in this precision medicine research systematic review, seven articles were excluded upon further review of full text due to the demographics of study participants not meeting inclusion criteria (study participants did not consist of underrepresented minority groups) or the study not being conducted within the United States, which was not apparent from the abstracts. Reasons for exclusion at this stage were explicitly noted (Figure 1). In cases of doubt, the decision was discussed with author H.Z. before proceeding with final decisions.

2.5 | Data extraction and synthesis

Once the final group of publications was established (n = 27), the following data were systematically extracted into tables from each article: study aims, methods, participant demographics, results, themes, discussion, conclusions, and future research/recommendations for practice. Individual study
biases were also collected, including those that were explicitly stated by the authors and those that were noted externally by reviewer E.F.

Themes were synthesized from each included paper based on the guidelines described here. First, each manuscript was read in-depth, noting the major themes and outcomes reported in each paper and developing a thematic framework to encompass all identified outcomes. This thematic framework was then applied to the extracted data and used to interpret and summarize the data. Authors H.Z. and R.P. acted as arbiters throughout the process, providing professional opinion and assisting with consensus regarding extraction, themes, and tables. Areas of disagreement during data synthesis were approached through discussion and, if required, by revisiting the source material until a consensus was achieved.

2.6 | Quality assessment and application of theoretical framework

Qualitative papers (n = 8) were assessed using the Critical Appraisal Skills Programme (CASP) for Qualitative Research to examine the reliability and relevance of the studies (CASP, 2018). Quantitative papers (n = 19) were assessed using the Joanna Briggs Institute (JBI) Critical Appraisal Tool for Analytical Cross-Sectional Studies to analyze the methodological quality and potential for bias in the studies (Moola et al., 2017). Two items on the JBI Critical Appraisal Tool, regarding measurement of the exposure and the condition, were not assessed because they were not relevant to this selection of quantitative studies. Author R.E. performed both the CASP and JBI quality assessments for all qualitative and quantitative papers.

Author E.F. applied the Socio-Ecological Model (SEM) theoretical framework to the introduction, study design and methods, results, and discussion sections of each study in order to characterize the various sociocultural and environmental factors that were addressed by each publication.

3 | RESULTS

3.1 | Overview

Of the 2,229 abstracts that were screened for inclusion, 34 full-text articles were assessed for eligibility for this systematic review focused on views of minority populations toward precision medicine research. Of the eligible publications, 27 studies met inclusion criteria and were evaluated for data extraction, quality assessment, and thematic analysis (Figure 1). Out of over 146,000 cumulative individuals included in the 27 studies, there were 102,421 White participants, 15,081 African American participants, 11,877 Asian American participants, approximately 4,500 Hispanic participants, and over 11,500 individuals in “other race” categories.

Five major themes were delineated from the included 27 articles: (a) knowledge and understanding of genetic testing and research; (b) engagement and participation in genetic
research; (d) concerns and barriers to participation in genetic testing and research; (e) cultural- and community-specific considerations in genetic research. Four studies addressed all five themes (Frazier, Calvin, Mudd, & Cohen, 2006; Hull et al., 2008; Murphy & Thompson, 2009; Pettey et al., 2015). The objectives, sample demographics, and major findings for all publications included in the systematic review are summarized in Table 1.

### 3.2 | Quality assessment and theoretical framework analysis

All publications had quality assessment scores of at least 6 out of 9 possible points (average: 7.1 points; range: 6 to 8 points) using the Critical Appraisal Skills Programme for qualitative studies \(n = 8\) papers and at least 3 out of 6 points possible (average: 4.8 points; range 3 to 6 points) using the Joanna Briggs Institute Critical Appraisal Tool for quantitative studies \(n = 19\) papers; Supporting Information). Two hundred eighty-seven participants were included in the qualitative studies, and 146,435 participants were included in the quantitative studies.

When the Socio-Ecological Model framework was applied to assess the sociocultural and environmental factors addressed in each publication, the vast majority of studies were found to have focused on the organizational/institutional and community influences on participants and study results (Supporting Information). Only 7 of the 27 publications addressed implications of their findings at the policy level (Almeling & Gadarian, 2014; Buseh, Kelber, Millon-Underwood, Stevens, & Townsend, 2014; Buseh et al., 2012; Dye et al., 2016; Hull et al., 2008; Rew, Mackert, & Bonevac, 2010; Sanderson et al., 2017), which could represent a lack of recognition or focus on the higher-level changes that are required to increase minority participation in genetic research. Three papers addressed all five levels of influence in the Socio-Ecological Model, none of which overlapped with the four studies assessing all themes described in this systematic review (Buseh et al., 2014; Dye et al., 2016; Sanderson et al., 2017).

Publications that addressed multiple levels of the SEM model in both study design and in discussion of study findings recognized the various layers of influence in society that could impact an individual's perspectives of and willingness to participate in genetic research. For example, Buseh et al. (2014) trained individuals known and trusted in the community as field interviewers (thereby increasing trust and establishing relationships at the interpersonal/social level), conducted the interviews at a mutually agreed upon place and time with all participants (to increase access to participation and reduce barriers at the organizational/institutional level), partnered with a community-based organization (CBO) and requested permission from the executive director of the CBO before study initiation (respectful engagement at the community level), and stated that it is important for healthcare professionals to engage with diverse racial/ethnic populations in order to develop culturally relevant policies to address public concerns toward genetics initiatives (thereby calling for changes at the policy level).

### 3.3 | Theme 1: Knowledge and understanding of genetic testing and research

Knowledge and understanding of genetics were typically defined using assessments of health literacy, familiarity with genetics terms, and participants’ interpretations of the definition of genetics. Nine of 27 articles assessed participants’ knowledge and understanding of genetics topics (Akinleye et al., 2011; Bloss et al., 2018; Buseh et al., 2014; Frazier et al., 2006; Hull et al., 2008; Murphy & Thompson, 2009; Nodora et al., 2016; Pettey et al., 2015; Rew et al., 2010). Overall, knowledge and understanding of genetics was reportedly limited among participants of all races and ethnicities, including White participants, in the general population in these nine articles. Many participants had heard of genetic-related topics such as genetic testing, genetic research, or the Human Genome Project, but few had a comprehensive understanding of these topics. Participants’ definitions of genetics often included concepts of inheritance, family history of disease, susceptibility and risks for developing disease, and beliefs about the origins of disease.

One of these nine studies specifically reported on differences in knowledge and understanding of genetics between White participants and other racial/ethnic groups (Akinleye et al., 2011). Akinleye et al. reported that African American participants had lower knowledge of Alzheimer's disease and genetic testing compared with White participants in their sample. Two studies examined how participants acquired knowledge of genetics by inquiring about sources of information; the primary resources for genetic information included healthcare providers and organizations, the Internet, and the media (Frazier et al., 2006; Rew et al., 2010).

### 3.4 | Theme 2: Engagement and participation in genetic research

Overall engagement with genetic research was divided into three subthemes and assessed participants’ motivations for participation (Subtheme A), willingness to participate (Subtheme B), and predictors of participation in genetic research (Subtheme C). Motivations (Subtheme A) included attitudes toward research, perceived benefits of participating, and
3.4.1 | Subtheme A: Motivations for participation

The majority of participants believed genetic research produces beneficial outcomes to society and that there

reasons to participate in genetic research. Willingness to participate (Subtheme B) was defined as participants’ reported intentions to participate in research, interest in receiving results from genetic testing, and actual uptake of genetic testing or consent for research. Predictors of participation (Subtheme C) included factors that were either positively or negatively correlated with willingness to participate in genetic research. Null findings were also included under this subtheme, such as variables that were not found to be correlated with participation rates. All 27 articles assessed at least one of these factors associated with engagement and participation.

### Table 1: Overview of included studies and thematic results

| Study | Design and study goals | Population | THEME 1: Knowledge and understanding of genetics | THEME 2: Engagement and participation in research |
|-------|------------------------|------------|---------------------------------|--------------------------------|
| Aagaard-Tillery (2006) | **Design:** Quantitative; in-person questionnaire  
**Goals:** To assess whether reproductive-aged women enrolling in a genetic study would demonstrate a bias in their willingness to participate in a repository for future genetic research | African Americans ($n = 1,727$), Hispanics ($n = 1,594$), Whites ($n = 1,576$), Asian Americans ($n = 40$), Native Americans ($n = 10$), “other” ($n = 55$) | – | – |
| Akinleye (2011) | **Design:** Quantitative; telephone and in-person surveys; randomization into two study arms  
**Goals:** To examine differences between African Americans and Whites in knowledge, attitudes, and motivations regarding genetic susceptibility testing for Alzheimer’s disease | Whites ($n = 249$), African Americans ($n = 64$) | – | – |
| Almeling (2014) | **Design:** Quantitative; cross-sectional online survey  
**Goals:** To examine public opinion on policy issues in genetics, including federal spending on genetic research, the perceived significance of genetic nondiscrimination laws, and clinicians’ involvement in direct-to-consumer genetic testing | Whites ($n = 1,584$), African Americans ($n = 206$), Hispanics ($n = 172$), “other” ($n = 138$) | – | – |

- 73% of women consented for unrestricted use of their samples in future genetic studies
- 73% of women consented for unrestricted use of their samples in future genetic studies
- 73% of women consented for unrestricted use of their samples in future genetic studies
are personal benefits to individuals who participate in genetic research (Akinleye et al., 2011; Buseh et al., 2014, 2012; Frazier et al., 2006; Freedman et al., 2013; Halbert, Gandy, Collier, & Shaker, 2006; Halbert, McDonald, Vadaparampal, Rice, & Jefferson, 2016; Hooper et al., 2013; Hull et al., 2008; Jenkins et al., 2011; Kinney et al., 2006; Lakes et al., 2013; Murphy & Thompson, 2009; Pettey et al., 2015; Rew et al., 2010; Sanderson et al., 2017). The most often cited reasons for participating in genetic testing and research were to learn more information, to contribute to the development of medical treatments and prevention of disease, and to positively impact future generations. Participants often cited benefits of participating for themselves, such as using the information obtained from testing to improve health, seek treatment, or for future planning. Participants recognized that genetic research is useful for the diagnosis and treatment of disease and felt that their participation could benefit future generations.
3.4.2 Subtheme B: Willingness to participate

Fifteen articles reported that the majority (defined as over 50%; range 57%–97%) of respondents in their sample were willing to participate in genetic testing or research and were willing to receive results from testing. This applied to studies that examined reported interest and intentions to participate (n = 7; Freedman et al., 2013; Halbert et al., 2006; Hooper et al., 2013; Hull et al., 2008; Murphy & Thompson, 2009; Pettey et al., 2015; Sanderson et al., 2017), as well as studies that measured definitive consent for genetic testing and

| Study | Design and study goals | Population | THEME 1: Knowledge and understanding of genetics | THEME 2: Engagement and participation in research |
|-------|------------------------|------------|-----------------------------------------------|-----------------------------------------------|
|       |                        |            | • Precision medicine literacy (familiarity with precision medicine terms) for all participants was an average of 50% (mean = 12 (SD = 6) on a 0 to 24 scale) | Subtheme A: Motivations Subtheme B: Willingness |
|       |                        |            | • Knowledge of medical genetics, including knowledge of inheritance, risks, and genetic testing implications, was generally low (65% average, SD = 17%) | – – |
|       |                        |            | • The majority of participants saw genetic testing as essential for diagnosis and treatment of disease | – |
|       |                        |            | • Anticipated future uses of genetic testing included determining risk for many diseases (79%), identifying more diseases before birth (74%), and paying attention to genetics aspects of disease for treatment (71%) | – |

**Notes:**
- Subtheme C: Predictors
  - Hispanics, Asian Americans
  - Higher genetics knowledge levels
- TABLE 1 (Continued)
- Buseh et al. (2014) Design: Quantitative; cross-sectional exploratory survey design
  - Goals: To examine the knowledge of medical genetics, group-based medical mistrust, and future expectations of genetic research and the influence of these measures on perceived disadvantages of genetic testing among Black African immigrants and/or refugees
  - Black African immigrants and refugees (n = 212)

| Study | Design: Quantitative; cross-sectional online survey design | Goals: To analyze the demographics of a sample of blood bank donors to inform on whether recruitment of blood bank donors for precision medicine research would produce participants representative of the United States. | Population | Subtheme A: Motivations | Subtheme B: Willingness |
|-------|----------------------------------------------------------|-------------------------------------------------------------------------------------------------|------------|------------------------|------------------------|
|       |                                                         |                                                                                                  |            |                        |                        |
|       |                                                         |                                                                                                  |            |                        |                        |
THEME 3: Practical considerations that facilitate participation

- Higher genetics knowledge levels were associated with fewer perceived disadvantages of genetic testing**
- Higher group-based medical mistrust and greater anticipated negative impacts of testing were associated with greater perceived disadvantages of genetic testing**

THEME 4: Concerns and barriers to participation

- Perceived disadvantages of genetic testing included insurance discrimination (71%), employment discrimination (39%), lack of government protection (26%), and emotional and interpersonal consequences (25%)
- 33% of participants expressed concerns about being viewed negatively by others if their family carried a faulty gene
- Group-based medical mistrust of healthcare providers and systems was prevalent; more than 50% of participants indicated that people of their ethnic group do not receive the same care as other ethnic groups
- Concerns about societal discrimination were cited by 33% of participants as a reason not to test

THEME 5: Cultural- and community-specific considerations

- 33% of participants expressed concerns about being viewed negatively by others if their family carried a faulty gene
- Group-based medical mistrust of healthcare providers and systems was prevalent; more than 50% of participants indicated that people of their ethnic group do not receive the same care as other ethnic groups
- Concerns about societal discrimination were cited by 33% of participants as a reason not to test

(Continues)
| Study                          | Design and study goals                                                                 | Population                                      | THEME 1: Knowledge and understanding of genetics | THEME 2: Engagement and participation in research |
|-------------------------------|--------------------------------------------------------------------------------------------|-------------------------------------------------|-------------------------------------------------|--------------------------------------------------|
| Buseh et al. (2012)           | **Design:** Qualitative; in-person focus group interviews  
**Goals:** To explore perspectives on genomics research and DNA biobanking among Black African immigrant community leaders and to discern how to best invite and sustain engagement of Black African immigrants in research endeavors. | Black African immigrant community leaders ($n = 27$) | –                                               | –                                                |
|                               |                                                                                           |                                                 | Reasons to be involved in genetics research included hope for positive impact on future generations and being empowered by information obtained from research | –                                                |
|                               |                                                                                           |                                                 | Subtheme A: Motivations                         | Subtheme B: Willingness                          |
|                               |                                                                                           |                                                 | • Reasons to be involved in genetics research included hope for positive impact on future generations and being empowered by information obtained from research | –                                                |
| Cox (2007)                    | **Design:** Quantitative; in-person survey  
**Goals:** To evaluate demographic and psychosocial factors associated with consent for genetic testing among a large sample of African Americans entered in a smoking cessation clinical trial | African Americans ($n = 745$)                  | –                                               | –                                                |
|                               |                                                                                           |                                                 | • 83% of participants consented to blood collection for future genetic testing and storage in biobank for at least 10 years | –                                                |
|                               |                                                                                           |                                                 | • 88% of participants gave permission to be contacted for future studies | –                                                |
| Culhane-Pera et al. (2017)    | **Design:** Quantitative; in-person survey  
**Goals:** To assess the feasibility of conducting genomic and pharmaco-genomic-based research for genetic variants that are relevant to the Hmong community using a community-based participatory research process | Hmong individuals ($n = 237$)                   | –                                               | –                                                |
|                               |                                                                                           |                                                 | • 85% of participants agreed to store their DNA (obtained from saliva sample) for future analyses about any topics | –                                                |
|                               |                                                                                           |                                                 | • 82% of participants agreed to share DNA with other researchers about similar topics (pharmaco-genomics and conditions that affect the Hmong community) | –                                                |
|                               |                                                                                           |                                                 | • 78% of participants agreed to be contacted for future research | –                                                |
**THEME 1: Knowledge and understanding of genetics**

- **Subtheme A: Motivations**
  - Reasons to be involved in genetics research included hope for positive impact on future generations and being empowered by information obtained from research.

- **Subtheme B: Willingness**
  - Conditions a research study should meet before participants would consider engaging included assurance of privacy and transparency regarding how genetic info would be used.
  - Participants cited preference for individual informed consent for every research project that desired to use banked DNA from participants; desired ability to withhold permission for use.

**THEME 2: Engagement and participation in research**

- **THEME 3: Practical considerations that facilitate participation**
  - Concerns about insurance and employment discrimination.
  - Concerns about confidentiality and researchers using genetic info for other research purposes that were not consented for.
  - Barrier to participation included disapproval of research for profit and patenting of findings.

**THEME 4: Concerns and barriers to participation**

- **THEME 5: Cultural- and community-specific considerations**
  - Cultural beliefs of the body remaining whole and intact upon death as a barrier to participation.
  - Personal health information should be kept private in African culture.
  - Genetics can be at odds with traditional understanding about illness.
  - Trusting a research project if an African community member is placed in a leadership position on the research team.
  - Desired culturally relevant education about purpose of research before consenting.
  - Fear of genetics being used to oppress or socially discriminate groups.
  - Facilitator of research participation included ensuring benefits are distributed back to community.

*Null* No demographic differences were found between those that gave consent and those that declined.

- Reasons for not participating included concerns about not benefiting from the study if not receiving individual results back.

(Continues)
Three studies reported consent rates lower than 50% in their sample (Halbert et al., 2016; Hensley Alford et al., 2011; Jazwinski et al., 2013). Halbert et al. reported a 31% intention to participate rate among African American participants ($n = 150$) for a hypothetical government-sponsored study with open data sharing and no option for participants to receive individual results.

| Study             | Design and study goals                                                                 | Population                                      | THEME 1: Knowledge and understanding of genetics | THEME 2: Engagement and participation in research |
|-------------------|----------------------------------------------------------------------------------------|------------------------------------------------|------------------------------------------------|------------------------------------------------|
| Dye et al. (2016) | **Design:** Quantitative; cross-sectional online survey  
**Goals:** To assess attitudes toward genetic testing and genetic research and to compare attitudes by racial group between African Americans and Whites | Whites ($n = 403$), African Americans ($n = 56$) | –                                               | –                                               |
|                    |                                                                                       |                                                 |                                                 | • The majority of both White and African American participants had never had genetic testing (93% vs. 88%, respectively) |
| Frazier et al. (2006) | **Design:** Qualitative; semi-structured focus group interviews  
**Goals:** To describe and compare the attitudes, knowledge, and beliefs of older adults from three ethnic groups about genetic testing and genetic research and to determine how these attitudes influence informed consent and decision-making about participation in genetic research | African Americans ($n = 9$), Hispanics ($n = 8$), Whites ($n = 6$) | • All groups included the concepts of inheritance and susceptibility to disease when defining genetics  
• Confusion regarding the meaning of genetic testing was prevalent in all groups  
• Sources of information about genetics included the Internet, consumer reports, television, and material distributed by the NIH and AARP | • Reasons for testing included physician recommendation to test, disease prevention, and value for future generations  
• African American participants did not agree that everyone values participation in genetic testing for the sole purpose of research  
• Participants from all groups agreed that families should be informed of genetic testing results to direct health promotion and disease prevention |
| Freedman et al. (2013) | **Design:** Quantitative; exploratory design; in-person; and telephone surveys  
**Goals:** To examine the views of African Americans and European Americans at risk for end-stage kidney disease on the value and use of genetic testing in research. | Whites ($n = 66$), African Americans ($n = 64$) | –                                               | • Reasons for wanting to know results from genetic testing included knowing health information about themselves, using results to improve health and plan ahead, and having the right to know information about themselves  
• The majority of participants would want to know results of genetic testing even if no treatment was available |
| Subtheme C: Predictors                                                                 | THEME 3: Practical considerations that facilitate participation | THEME 4: Concerns and barriers to participation | THEME 5: Cultural- and community-specific considerations |
|--------------------------------------------------------------------------------------|---------------------------------------------------------------|------------------------------------------------|--------------------------------------------------|
| • African Americans were less likely to want to participate in research that would use their DNA, create cell lines from their DNA for future studies, or share their DNA with a private company** | • African American participants would be interested in testing only when the information obtained would be provided back to individual participants | • Barriers to testing included not wanting information about personal genetic susceptibility, concerns for disrupting family relationships, and concerns about insurance and employer discrimination | • Culturally relevant beliefs were incorporated in participants’ understanding of genetics, such as relating genetics to a curse or sickness caused by someone’s ill-wishing |
| • African Americans were less likely to agree that the use of genetic testing should be promoted and should be available to those who want to use it compared with White participants** | • All groups suggested that providers should avoid medical jargon and technical terminology when consenting, and to establish alertness and orientation in potential participants | • Some participants lacked confidence in the interpretation and validity of genetic test results | • Participants were apprehensive that passing along information from genetic testing to family would cause illness or shame |
| • African Americans were less likely than Whites to want to know results from testing even if their healthcare provider already knew results or if it was easy/cheap for their provider to order the testing* | • Participants thought providers should emphasize the voluntary nature of consent for hospitalized older adults who might not perceive consent as voluntary | • Participants would use their DNA, create cell lines from their DNA for future studies, or share their DNA with a private company** | • (Null) There were no significant differences between African American and White participants in their desire to know results from testing |

(Halbert et al., 2016). Jazwinski et al. and Hensley Alford et al. reported lower participation rates among a subset of their participants in their studies measuring actual consent; namely 41% of Asian American participants (n = 51; Jazwinski et al., 2013) and 30% of African American participants (n = 3,740; Hensley Alford et al., 2011) were willing to consent for genetic testing.
TABLE 1 (Continued)

| Study               | Design and study goals                                                                 | Population                      | THEME 1: Knowledge and understanding of genetics | THEME 2: Engagement and participation in research |
|---------------------|----------------------------------------------------------------------------------------|---------------------------------|-------------------------------------------------|-------------------------------------------------|
| Halbert et al. (2006) | **Design:** Quantitative; cross-sectional structured telephone interviews            | African Americans ($n = 128$) | –                                                | **Subtheme A:** Motivations                      |
|                     | **Goals:** To describe intentions to participate in smoking and genetics research and to determine factors that are associated with participation intentions among African American smokers |                                 |                                                 | **Subtheme B:** Willingness                       |
|                     |                                                                                        |                                 |                                                 | • Most participants (60%) believed there are benefits to people who participate in medical research; benefits included improving quality of health care and being empowered to change smoking behavior |
|                     |                                                                                        |                                 |                                                 | • Majority of participants (58%) reported they would be willing to participate in research to identify genetic risk factors for smoking |
| Hensley Alford et al. (2011) | **Design:** Quantitative; prospective observational study (online and in-person survey and consent process) | African Americans ($n = 3,740$), Whites ($n = 2,608$) | –                                                |                                                 |
|                     | **Goals:** To evaluate whether gender, race, and education status influences interest and participation in a multiplex genetic susceptibility test using a population-based sample of healthy adults |                                 |                                                 | • Positive expectations about participating in cancer genetics research included helping future generations (86%), contributing to strategies to prevent and treat cancer (84%), helping people who have an increased risk for cancer (77%), and getting information about how to detect and treat cancer for themselves (42%) |
| Hooper et al. (2013)  | **Design:** Quantitative; cross-sectional in-person survey                              | Hispanics ($n = 26$), Whites ($n = 8$) | –                                                |                                                 |
|                     | **Goals:** To examine aspects of study design that are important to individuals at risk for Alzheimer's disease in determining whether they would be willing to undergo genetic testing, learn the results, and participate in the study. | 10 of 26 Hispanic participants were living in Mexico |                                                 | • Overall rates of participation in testing were 30% among African Americans and 55% among White participants** |
|                     |                                                                                        |                                 |                                                 | • Reasons to participate in genetic testing and a research trial included wanting to help future generations, benefits outweighing the risks, wanting to know for future planning |
|                     |                                                                                        |                                 |                                                 | • 65% of participants reported they may be or would definitely be interested in learning their genetic status for familial Alzheimer's disease |
|                     |                                                                                        |                                 |                                                 | • 62% of respondents reported interest in participating in a clinical trial; 26% reported they may be interested in participating |
| Subtheme C: Predictors | THEME 3: Practical considerations that facilitate participation | THEME 4: Concerns and barriers to participation | THEME 5: Cultural- and community-specific considerations |
|-----------------------|-------------------------------------------------------------|-------------------------------------------------|----------------------------------------------------------|
| • Participants who perceived greater benefits to participating in research were most likely to be willing to participate (OR = 3.2)** | • Limitations and risks endorsed by participants included not knowing how results would be used, concerns about the result not being accurate, and feeling no control over behavior | • 42% of respondents believed that participants in research are taken advantage of or exploited; however, this was not significantly associated with a decreased willingness to participate in research |
| • Participants who reported fewer concerns about the limitations and risks of research were more likely to be willing to participate (OR = 0.90)** | • Facilitators included being given free healthcare services and the study assessing a health condition the individual was worried about | • Fear of being labeled or treated differently by family members or by a physician was cited as a risk of testing |
| • Respondents with higher distrust in researchers were less likely to participate* | • 45% of respondents reported more participation facilitators than barriers, 9% had an equal number of barriers and facilitators, and 46% reported more participation barriers | • 57% of participants had a negative expectation that participating in research could lead to results being used to develop cancer drugs that someone like them could not afford |
| • Beliefs about positive expectations for research, concerns about privacy, distrust in researchers, and negative expectations about impact of research did not have significant associations with likelihood of participation | • Negative expectations about participating in research included researchers using results for profit (34%), loss of privacy (40%), obtaining information they did not want to know (43%), and loss of legal rights if something bad happened after enrolling in study (27%) | • Barrier to participation included difficulty getting to where the study was being conducted (63%) |
| • African Americans were less likely to complete the baseline invitation survey about personalized genomics research (first step in study) compared with Whites (33% vs. 36%; OR = 0.88)* | • Barriers to participating in research included not knowing who could obtain their personal information (60%) and the results not being made available to each participant (59%) | • Participants were more likely to report willingness to participate if someone from their racial group was conducting the study |
| • African Americans were less likely to visit the Web site for more information (second step) than Whites (26% vs. 40%; OR = 0.52)** | • Concerns about a research trial’s risks not outweighing the benefits were cited as a primary reason not to participate in genetic testing and research | • 65% of participants believed there are benefits to participating in research 
• 45% of respondents reported being empowered by the research included not knowing how results would be used, concerns about the result not being accurate, and feeling no control over behavior |
| • African Americans were significantly less likely to be tested than Whites (OR = 0.35)**; race was the only factor significantly associated with participation in genetic testing | • 31% of participants reported they may be interested in undergoing genetic testing and research | • English-speaking participants more frequently endorsed a willingness to participate in research trials with higher risks compared with Spanish-speaking participants |

(Continues)
3.4.3 | **Subtheme C: Predictors of participation**

Factors that clearly predicted a higher likelihood of participating in research included greater perceived benefits and values to participating in research (Bloss et al., 2018; Halbert et al., 2006; Sanderson et al., 2017), fewer concerns about the limitations and risks of research (Halbert et al., 2006; Sanderson et al., 2017), greater willingness to share personal health information (Bloss et al., 2018), fewer informational needs (Sanderson et al., 2017), and higher satisfaction with healthcare providers (Sheppard et al., 2018). Less favorable views about the value of research predicted a lower willingness to participate in research (Bloss et al., 2018).

Importantly, while some studies reported a correlation between being a member of a racial/ethnic minority group (Hispanic, African American, or Asian American) and decreased willingness to participate (n = 5; Aagaard-Tillery et al., 2006; Bloss et al., 2018; Dye et al., 2016; Hensley Alford et al., 2011; Sanderson et al., 2017), other studies found that race and ethnicity were not predictors of consent for research.
Subtheme C: Predictors

- Patients who were more private (OR = 0.69)* and less trusting in researchers (OR = 0.57)* were more likely to want to know about research being done with their sample in both scenarios (anonymous vs. identifiable).

- African American respondents (OR = 1.91)* were more likely to want their permission to be sought in the anonymous scenario, as well as those who were less religious (OR = 0.52)*, more private (OR = 0.84)*, and less trusting of researchers (OR = 0.40)*.

THEME 3: Practical considerations that facilitate participation

- Majority of participants felt that it was moderately or very important for them to be informed about research that would be done with their sample, regardless of whether the sample was donated anonymously (72%) or was identifiable (81%).

- 57% of participants would require their permission to be sought before samples could be used in other research while the remainder would be satisfied with only notification of research being done.

- Some respondents desired to receive results or benefit directly from the research being done with their donated sample.

- Participants wanted upfront reassurance that their confidentiality would be protected by researchers.

THEME 4: Concerns and barriers to participation

- Concerns about the research topic and concerns about confidentiality and privacy drove participants’ desire to know about research being done with their donated sample.

(Continues)
of biospecimens that had already been donated to research. African Americans and Hispanic participants were more likely to prefer to discard their sample after initial study use than White participants (Aagaard-Tillery et al., 2006). African Americans were less likely to agree to subsequent use of their biospecimens in future research compared with White participants (Aagaard-Tillery et al., 2006). Participants who were more private and less trusting of researchers were more likely to want to be informed of future research utilizing their sample (Hull et al., 2008). Individuals were more likely to prefer permission to

| Study                                    | Design and study goals                                                                 | Population                          | THEME 1: Knowledge and understanding of genetics | THEME 2: Engagement and participation in research |
|------------------------------------------|----------------------------------------------------------------------------------------|-------------------------------------|-------------------------------------------------|-------------------------------------------------|
| Jenkins et al. (2011)                    | **Design:** Qualitative; in-person focus group interviews                              | African Americans ($n = 32$), Whites ($n = 5$), “other” ($n = 1$) | –                                               | • Reasons for participation in the study included being interested in learning more and helping others • Participants felt positive overall about the appearance of the specimen collection kit that was mailed to their homes |
| Kinney et al. (2006)                     | **Design:** Quantitative and qualitative methods                                        | African Americans ($n = 161$)      | –                                               | • Motivating factors to participate in genetic testing research included family and personal motivations (62%), educational or informational motivations (28%), and the perspective that participation could have a positive and broad community impact • 54% of participants chose to participate in pretest education and counseling; 83% of those participants accepted testing results and 17% declined receiving the results |

Subtheme A: Motivations

Subtheme B: Willingness
| Subtheme C: Predictors | THEME 3: Practical considerations that facilitate participation | THEME 4: Concerns and barriers to participation | THEME 5: Cultural- and community-specific considerations |
|------------------------|---------------------------------------------------------------|-------------------------------------------------|---------------------------------------------------------------|
| African American participants reported a shorter time frame from receiving the specimen collection kit to providing a specimen | Participants reported positive views of monetary incentives and felt the incentives increased legitimacy of study, but were not a primary decision-making factor for participation | Participants were concerned about lack of information on the consent form regarding when their samples would be destroyed and how long they would be stored, as well as no information on return of individual results | African American participants reported their child’s father expressing concern about how their biologic samples would be used by the government |
| • Factors that predicted testing acceptance included increased perceived risk of being a mutation carrier (OR = 4.1)*, older age (OR = 6.9)*, and higher levels of cancer genetics knowledge (OR = 1.5)* | • Respondents noted that reminder telephone calls had positive effects on their participation | • Participants in all groups cited challenges of convincing their child’s father to participate in research and stated this was the biggest barrier to participation in specimen donation | • Participants expressed personal concerns about the government using their biologic material |
| • (Null) No associations were observed between test uptake and baseline psychological distress, fatalistic beliefs about cancer, participation in prior genetic research, social support, or religious coping style | • Participants suggested researchers develop materials targeting fathers or including advice for mothers on how to encourage the father to participate | • Participants reported concerns about the safety and sterility of the collection kit, as well as difficulty with the methods of sample collection for themselves and their child | • African American participants reported their child’s father expressing concern about how their biologic samples would be used by the government |
| • Reasons for declining to participate included lack of interest (54%), personal problems (6%), and negative test results in other relatives (4%) | • Participants suggested researchers develop materials targeting fathers or including advice for mothers on how to encourage the father to participate | • Participants reported concerns about the safety and sterility of the collection kit, as well as difficulty with the methods of sample collection for themselves and their child | • Participants expressed personal concerns about the government using their biologic material |
| • 53% of participants thought their regular healthcare provider did not have adequate knowledge to provide genetics services and lacked education and training | • Participants who did not return a specimen stated that they preferred to receive individual results | • Participants reported concerns about the safety and sterility of the collection kit, as well as difficulty with the methods of sample collection for themselves and their child | • Participants expressed personal concerns about the government using their biologic material |

(Continues)

be sought for future research use of an anonymously donated sample if they were African American, less religious, more private, or less trusting of researchers (Hull et al., 2008). However, these findings were typically presented by only one study each and were unreplicated among this selection of articles.

3.5 | Theme 3: Practical considerations about studies that facilitate participation in research

Participants stated preferences for practical aspects of a research study that would increase their willingness to participate in the
study. Fifteen articles described facilitating factors (Aagaard-Tillery et al., 2006; Almeling & Gadarian, 2014; Bloss et al., 2018; Buseh et al., 2012; Frazier et al., 2006; Freedman et al., 2013; Halbert et al., 2016; Hull et al., 2008; Jenkins et al., 2011; Lakes et al., 2013; Murphy & Thompson, 2009; Pettey et al., 2015; Simon, Tom, & Dong, 2017). The primary facilitators of participation were receiving direct benefits including return of individual results to participants \((n = 8);\) Frazier et al., 2006; Halbert et al., 2016; Hull et al., 2008; Jenkins et al., 2011; Lakes et al., 2013; Murphy & Thompson, 2009; Pettey et al., 2015; Simon et al., 2017), fulfillment of information needs \((n = 6);\) Buseh et al., 2012; Hull et al., 2008; Lakes et al., 2013; Pettey et al., 2015; Rew et al., 2010; Sanderson et al., 2017; Simon, Tom, & Dong, 2017), and upfront assurance of privacy and confidentiality \((n = 3);\) Buseh et al., 2012; Hull et al., 2008; Pettey et al., 2015). Participants desired direct benefits, such as monetary compensation, free healthcare services, or hospitable accommodation while participating, as well as to receive individual results from testing (Frazier et al., 2006; Halbert et al., 2016; Hull et al., 2008; Jenkins et al., 2011; Lakes et al., 2013; Murphy & Thompson,
Common information needs included wanting to know about the logistics of the study, the validity of the test, the context of the disease being studied, whether future research would utilize the samples, and the conduct of the researchers and institutions involved in the study (Buseh et al., 2012; Hull et al., 2008; Lakes et al., 2013; Pettey et al., 2015; Rew et al., 2010; Sanderson et al., 2017).

Other facilitators focused on preferences and expectations about the informed consent process, study materials, or return of results process (Frazier et al., 2006; Jenkins et al., 2011; Lakes et al., 2013; Sanderson et al., 2017). Participants in three studies cited a preference for researchers to ask permission before using their donated sample in future research (Aagaard-Tillery et al., 2006; Buseh et al., 2012; Hull et al., 2008). Several concrete methods to improve participation rates were also mentioned, such as reminder phone calls to participants, spreading awareness about ongoing studies through word of mouth, allowing alternative specimen types other than blood, and increasing clinician involvement in testing (Almeling & Gadarian, 2014; Jenkins et al., 2011; Murphy & Thompson, 2009; Simon et al., 2017).
### TABLE 1 (Continued)

| Study         | Design and study goals                                                                 | Population          | THEME 1: Knowledge and understanding of genetics | THEME 2: Engagement and participation in research |
|---------------|----------------------------------------------------------------------------------------|---------------------|-------------------------------------------------|-------------------------------------------------|
| Murphy and Thompson (2009) | **Design:** Qualitative; in-person focus group interviews  
**Goals:** To explore Black participants' attitudes toward and willingness to participate in genetic studies of psychiatric disorders | African Americans ($n = 18$), Whites ($n = 8$) | - Most participants described their interpretation of genetics as traits that are passed down (39%), and many had a superficial knowledge of genetics terminology (36%)  
- Participants' understanding of genetic research included experimental procedures (28%) and the purpose as trying to understand the origins of disease (22%)  
- Participants acknowledged their incomplete understanding of genetic research (25%) and felt that research is inaccurately represented in the media  
- Beliefs about causes of psychiatric disorders included environmental causes and stressful life events (27%), family and childhood upbringing (19%), lifestyle-related personal habits (13%), and substance abuse | - Perceived advantages and benefits of genetic research included understanding the origins of disease (48%), preventing or curing disease with targeted treatment (35%), keeping society better informed, and desigmatizing certain disorders through removal of personal blame  
- Reasons to participate included the desire to contribute to society and fellow humans, and having a personal or family history of the disorder being investigated | - All of the participants indicated a willingness to participate in other ongoing research studies |
| Nodora et al. (2016) | **Design:** Quantitative; in-person survey, randomized into two study arms  
**Goals:** To assess Hispanic individuals' willingness to donate biospecimens for research and determine whether the type of healthcare provider approaching the participants impacts rates of consent | Hispanic women ($n = 140$) | - Approximately 85% of all participants had limited health literacy; however, this was not a barrier to consent for participation | - Consent for biospecimen donation for research was 97% among participants consented by a physician and 93% among participants consented by a research assistant (nonsignificant difference) |
Sanderson et al., 2017; Simon et al., 2017), use of participants’ genetic information for other research purposes that were not consented for or were undesirable (n = 7; Buseh et al., 2012; Halbert et al., 2006, 2016; Hull et al., 2008; Jenkins et al., 2011; Pettey et al., 2015; Jenkins et al., 2011; Pettey et al., 2015; Simon et al., 2017), concerns about insurance or employment discrimination (n = 5; Akinleye et al., 2011; Buseh et al., 2014, 2012; Frazier et al., 2006; Pettey et al., 2015), concerns about risks or harms of the study procedure (n = 5; Hooper et al., 2013; Jenkins et al., 2011; Murphy & Thompson, 2009; Pettey et al., 2015; Simon et al., 2017), and individual results not being made available to participants (n = 5; Culhane-Pera et al., 2017; Halbert et al., 2016; Jenkins et al., 2011; Lakes et al., 2013; Simon et al., 2017).

Other barriers to testing included anticipation of negative emotional or interpersonal consequences, doubts about the
validity of the testing, and lack of actionable steps to improve health. Three studies reported disapproval of research for profit and patenting of findings as a barrier to participation (Buseh et al., 2012; Halbert et al., 2016; Sanderson et al., 2017).

### 3.7 | Theme 5: Cultural- and community-specific considerations about genetic research

Cultural- and community-specific considerations about genetic research (Theme 5) often involved facilitators (Theme...
### Subtheme C: Predictors

| THEME 3: Practical considerations that facilitate participation | THEME 4: Concerns and barriers to participation | THEME 5: Cultural- and community-specific considerations |
|---------------------------------------------------------------|-------------------------------------------------|--------------------------------------------------------|
| • Participants were agreeable to participating but wanted more information and desired assurance of privacy before participating. | • Concerns about participating included concerns about the test being painful and not being sure that a genetic study of hypertension would be helpful. | • Culture influenced family teaching about disease and included home remedies. |
| • One participant stated they would only participate if the results would be given back to individuals after the study. | • Concerns about privacy included wanting the sample to only be used for the particular study consented for. | • Participants mentioned needing to schedule testing around their job as a logistical consideration of participation. |

- Parents and older adolescents expressed greater concern about the credibility of testing (validity, reliability, accuracy, and specificity of the test) than younger adolescents.
- Factors to consider when making the decision to participate in testing included how testing is done, credibility of testing, purpose of testing, outcomes of testing, history of testing, cost of testing, and meaning of test.
- Participants’ opinions varied on the appropriate age to test, but was an average of about 18 years.
- Some participants (mostly older adolescents) mentioned concerns about potential negative impacts of testing.

3) and barriers (Theme 4) to participation but were specifically defined as current beliefs, attitudes, or actions that were likely influenced by historical system-wide practices affecting certain groups of people (organizational influences) or cultural- and community-specific beliefs (community/group influences) about genetics and research. Fifteen of 27 articles reported results that addressed cultural, community, and organizational/institutional considerations about genetic research (Buseh et al., 2014, 2012; Frazier et al., 2006; Halbert et al., 2006, 2016; Hooper et al., 2013; Hull et al., 2008; Jazwinski et al., 2013;...
The majority of participants’ organizational- and community-influenced considerations about research constituted barriers to participation. Overall, in this selection...
Subtheme C: Predictors

- Black or African American participants expressed the lowest willingness to participate in the biobank (56%; OR = 0.58)* compared with White participants (70%)
- Participants were more willing to participate in the biobank if they perceived more benefits (OR = 8.1)*, had fewer concerns about participating (OR = 0.32)*, had fewer information needs (OR = 1.62)*, and were less religious (OR = 0.68)*
- Respondents were less willing to participate if they had lower levels of trust in medical researchers and the healthcare system, higher levels of worry about their privacy, and stronger feelings about the importance of keeping health information private*

THEME 3: Practical considerations that facilitate participation

- Willingness to participate was slightly but significantly higher in a controlled data sharing model (68%) compared with an open data sharing model (65%)*
- Information needs included wanting to know if a researcher misused health information in the biobank (86%), what kind of knowledge would result from sample use (84%), who makes sure that health info is used in the right way (84%), if health info could be used by insurance companies (79%), the types of research that would be done (74%), who runs the biobank (73%), how the biobank covers cost (60%), if health info would be used by drug companies to make money (59%)

THEME 4: Concerns and barriers to participation

- Perceived concerns about participating included worrying about privacy (51%), worry about sharing of medical record (45%), worry about how researchers would use health info (41%), worry about genetic info being shared (38%), worry about research being done they did not want a part in (37%), and worry that someone would make money using their health info (36%)
- 90% of participants agreed health information privacy was important to them; 64% agreed that they worried about the privacy of their health information

THEME 5: Cultural- and community-specific considerations

- 64% agreed that they trusted their healthcare system, and 61% agreed that they trusted medical researchers

(Continues)
to remain whole upon death (negating the ability to provide biospecimen), group-based medical mistrust in providers and healthcare systems, fear of genetics being used to socially oppress certain groups, concerns about government use of participants’ biological material, doubts that research findings would be beneficial to minority communities, and lack of physical access, awareness, and logistical constraints to participation in research (Buseh et al., 2014, 2012; Frazier et al., 2006; Halbert et al., 2006, 2016; Kinney et al., 2006; Lakes et al., 2013; Murphy & Thompson, 2009; Pettey et al., 2015; Simon et al., 2017).

Cultural considerations that facilitated participation in research included trusting a research study if a member of the community was involved in the research team, positive feelings of trust in medical researchers, and beliefs that research findings would benefit minority communities (Buseh et al., 2012; Hull et al., 2008; Sanderson et al., 2017; Simon et al., 2017).

### 3.8 Population-specific findings

Ten studies assessed the views and attitudes of participants from racial/ethnic minority populations only (Buseh et al., 2014, 2012; Cox et al., 2007; Culhane-Peria et al., 2017; Halbert et al., 2006, 2016; Kinney et al., 2006; Nodora et al., 2016; Pettey et al., 2015; Simon et al., 2017), whereas the remainder of the articles (n = 17) included individuals from majority and minority groups.

African American participants were the most studied population among the publications included in this systematic review (n = 22; Buseh et al., 2012; Frazier et al., 2006; Murphy & Thompson, 2009; Sheppard et al., 2018) (Aagaard-Tillery et al., 2006; Akinleye et al., 2011; Almeling & Gadarian, 2014; Blosse et al., 2018; Buseh et al., 2014; Cox et al., 2007; Dye et al., 2016; Freedman et al., 2013; Halbert et al., 2006, 2016; Hensley Alford et al., 2011; Hull et al., 2008; Jazwinski et al., 2013; Jenkins et al., 2011; Kinney et al., 2006; Pettey et al., 2015; Rew et al., 2010; Sanderson et al., 2017). Five studies reported that African American participants were less likely to participate in genetic testing or research (Aagaard-Tillery et al., 2006; Blosse et al., 2018; Dye et al., 2016; Hensley Alford et al., 2011; Sanderson et al., 2017), while four studies did not support an association between African American race and likelihood of participating in research (Cox et al., 2007; Freedman et al., 2013; Jazwinski et al., 2013; Sheppard et al., 2018).

Ten studies included Asian Americans in their study populations (Aagaard-Tillery et al., 2006; Blosse et al., 2018; Culhane-Peria et al., 2017; Hull et al., 2008; Jazwinski et al., 2013; Lakes et al., 2013; Rew et al., 2010; Sanderson et al., 2017; Sheppard et al., 2018; Simon et al., 2017). High consent rates among Asian American participants were reported by Culhane-Peria et al., and no difference between participation rates among Asian Americans and participants of other races/ethnicities was reported by Jazwinski et al. and Sheppard et al. However, Blosse et al. reported that Asian
American participants were less likely than other groups to indicate interest in a precision medicine research study.

Nine studies included Hispanic individuals in their study populations (Aagaard-Tillery et al., 2006; Almeling & Gadarian, 2014; Frazier et al., 2006; Hooper et al., 2013; Hull et al., 2008; Jazwinski et al., 2013; Lakes et al., 2013; Nodora et al., 2016; Rew et al., 2010). Two studies reported a lower willingness to participate in genetic testing and research among Hispanic participants compared with other ethnic groups (Aagaard-Tillery et al., 2006; Bloss et al., 2018). Conversely, Jazwinski et al. described similar rates of participation in research between Hispanic participants and other ethnic groups, and Nodora et al. reported high rates of consent for research among their all-Hispanic participant population. Of note, three studies did not clearly report the number of Hispanic individuals in their study population (Hull et al., 2008; Lakes et al., 2013; Sanderson et al., 2017).

Nine publications grouped individuals of races/ethnicities other than those specified separately in the study into an “other race” category (Bloss et al., 2018; Hull et al., 2008; Sheppard et al., 2018) (Aagaard-Tillery et al., 2006; Almeling & Gadarian, 2014; Hull et al., 2008; Jazwinski et al., 2013; Lakes et al., 2013; Sanderson et al., 2017). Overall, details were lacking regarding how this category was defined in each study as well as the specific racial/ethnic composition of the individuals placed within this category. Lakes et al. stated that individuals who did not provide a response for their race/ethnicity constituted a portion of participants included in their “other race” category (Lakes et al., 2013). Only one study specified the race or ethnicity of some participants in the “other race” category (Sheppard et al., 2018).

Five studies included smaller subpopulations of racial or ethnic minority groups, including Native Americans (n = 5 studies; 1,284 cumulative participants; Aagaard-Tillery et al., 2006; Bloss et al., 2018; Hull et al., 2008; Lakes et al., 2013; Sanderson et al., 2017), Iranians (Lakes et al., 2013), and Native Hawaiians or Pacific Islanders (Sanderson et al., 2017). Two publications included individuals who identified with more than one race/ethnicity (Lakes et al., 2013; Sanderson et al., 2017). It is unknown whether individuals reporting more than one race/ethnicity were included in the “other race” category of the other publications, highlighting the lack of detailed demographic reporting among research studies.

4 | DISCUSSION

This systematic review summarizes 13 years’ worth of literature describing the role of race and ethnicity in views toward and willingness to participate in precision medicine research. Most strikingly, the majority of study participants of all races and ethnicities in these studies were interested in undergoing genetic testing and participating in genetic research. Although understanding of genetics was generally low, participants recognized the value of genetic research
and described numerous motivations to participate in genetic testing and research, which commonly involved learning more information, contributing to the development of medical advances, and positively impacting future generations. While a few publications reported lower rates of participation among racial/ethnic minority populations and the range of participation rates in studies reporting majority participation was broad (57%–97%), most studies did not support the association between lower participation rates and being a member of a racial/ethnic minority group. Although the type of genetic research varied and the participant pool likely represents community members who might be more willing to participate in research in general, the overall positive view toward participation in genetic research dispels some previous assumptions in the field that individuals from racial/ethnic minorities in the general population are uninterested in genetic research (Corbie-Smith et al., 1999).

This finding is supported by studies of both hypothetical consent (Freedman et al., 2013; Halbert et al., 2006, 2016; Hull et al., 2008; Murphy & Thompson, 2009; Pettey et al., 2015; Sanderson et al., 2017) and actual consent (Aagaard-Tillery et al., 2006; Cox et al., 2007; Culhane-Pera et al., 2017; Hensley Alford et al., 2011; Jazwinski et al., 2013; Kinney et al., 2006; Nodora et al., 2016; Sheppard et al., 2018) for participation in genetic testing and research, further emphasizing the validity of this result.

Participants described many practical factors that increased or decreased their likelihood of participating in genetic research, which have direct implications for future research studies that aim to recruit diverse populations. Many of these practical considerations for study design have been described previously (Catz et al., 2005; Claw et al., 2018; Murphy & Thompson, 2009; Swanson & Ward, 1995; Yancey et al., 2006). Viewing these facilitating factors and obstacles to participation through the lens of the Socio-Ecological Model enables a more comprehensive understanding of the potential explanations that underlie participants’ preferences for genetic research studies. For example, many reported barriers to participation might reflect broader societal or institutional influences on the public’s perspectives of or access to genetic testing and research. Kinney et al. reported that only 18% of participants indicated that they would have undergone genetic testing had it not been accessible and available through the research study (Kinney et al., 2006). Therefore, the commonly cited participation barrier of not receiving individual genetic results might indicate a broader institutional barrier to accessing genetic testing services rather than simply an individual preference for genetic results from research. Recognizing the multiple layers of societal influence on reported barriers and facilitators to participation might lead to a greater willingness among researchers to incorporate participants’ preferences into study design.

Several areas for improvement were consistently noted among the 27 studies included in this systematic review. The most frequent study weaknesses involved lack of clear reporting of participant demographics, ambiguous groupings of participants of different races/ethnicities, and limited inclusion of minority populations other than African Americans, Asian Americans, and Hispanic participants. Lack of demographic details was illustrated in particular by several publications that did not specify the racial identity of their Hispanic participants (Hull et al., 2008; Lakes et al., 2013; Sanderson et al., 2017). Hispanic ethnicity is commonly reported in a separate category from race, and in some cases, there was an inability to form conclusions about study findings that were both racially and ethnically specific and comprehensive. For example, there was an inability to determine the number of participants who were Hispanic and White or Hispanic and another racial group such as African American. Also, placing participants into an “other race” category without defining the demographics of this group reduced the authors’ ability to form racial- and ethnicity-specific conclusions about study findings. Additionally, qualitative studies occasionally grouped White participants and individuals from racial/ethnic minorities into the same focus groups (Hooper et al., 2013; Jenkins et al., 2011; Murphy & Thompson, 2009). For instance, although the explicit research goal of Murphy et al. was to explore Black participants’ attitudes toward genetic studies of psychiatric disorders, the authors included eight White participants in their study population and did not differentiate the data by racial group (Murphy & Thompson, 2009). Alternative focus group designs that distinguish or exclude White participants would have enabled better comparison of views between racial/ethnic groups. Lastly, although African Americans, Asian Americans, and Hispanic individuals constitute the majority of racial/ethnic minority populations in the United States, there is a clear need for further research on other racial/ethnic minority populations, including American Indians, Alaskan Native peoples, and multiracial individuals (File, 2018). All of these limitations persisted even in studies that purposefully recruited underrepresented groups, and ultimately reduced the ability to accurately interpret results from studies that had great potential to provide insight into race- and ethnicity-based differences in views toward precision medicine research. There is an urgent need for better demographic reporting in studies that aim to recruit diverse populations.

The limitations of this systematic review are important to acknowledge. Most notably, there are a number of factors that intersect with race and ethnicity which were not investigated by this systematic review; for example, socioeconomic status, age, gender, sexual orientation, disability status, geographical location, national origin/level of acculturation, and political affiliation intersect with race/ethnicity and might impact attitudes toward precision medicine research and
willingness to participate in research endeavors (Andersson, Gadarian, & Almeling, 2017; Crenshaw, 1989; Hamilton et al., 2016; Kolor et al., 2017; Murphy & Thompson, 2009). Although many of the 27 included studies that reported high consent rates involved open data sharing research scenarios, examining whether participation rates varied based on type of consent model and data sharing restrictions was not a primary outcome of this systematic review. The authors recognize that further research assessing the non-White public's views toward open and closed data sharing models would be a valuable addition to the findings from this synthesis of literature. It is also important to note that the research settings varied (briefly outlined in Table 1); variability in each study's population, recruitment process, and setting could impact overall results, and the socioecological factors of each individual study should be taken into consideration when interpreting findings from this review (outlined in Supporting Information). Because both qualitative and quantitative study designs were incorporated, the findings may be partially skewed due to quantitative study designs that utilized researchers' preselected response options as compared to the open-ended questions traditional of qualitative study designs. Additionally, individuals who engage in research studies might be more motivated and willing to become involved in genetic research than individuals who did not participate; thus, it is unknown whether the high participation rates reported across all studies are truly reflective of the general population.

The timeframe of this systematic review was broad, encompassing 13 years of literature on the public's views toward genetic research. While the wide timeframe strengthened the reliability of the findings, the public's attitudes toward and awareness of genetic research are dynamic (Henneman et al., 2013). A systematic literature review restricted to a more recent timeframe might reveal interesting variations in trends due to the implementation of the Genetic Information Nondiscrimination Act in 2008 or the recent rise in popularity and prevalence of direct-to-consumer genetic testing, which might influence the public's acceptance of and willingness to participate in precision medicine research (Agurs-Collins et al., 2015). Additionally, because of the broad timeline of this review and the relatively newer use of the term “precision medicine,” the authors acknowledge that focusing on genetic aspects of precision medicine research does not encompass all components of precision medicine research. This systematic review might also be limited by publication bias in that only original research published in a peer-reviewed journal was accepted for inclusion, as opposed to unpublished dissertations and scientific conference abstracts. However, this analysis did incorporate null findings with respect to race/ethnicity and willingness to participate in precision medicine research, which might partially mitigate negative publication bias. Finally, the authors acknowledge that not all publications that would have met inclusion criteria were ascertained by the six databases searches. This might be due to inherent weaknesses in search criteria but could also represent broader deficiencies in identifiability of publications, such as lack of descriptive key words, which resulted in a reduced ability to detect all relevant publications.

In light of the results of this systematic review, the authors highlight the following research practices and participant preferences that could be incorporated in future precision medicine research studies, many of which have been noted previously (Catz et al., 2005; Claw et al., 2018; Giuliano et al., 2000; Swanson & Ward, 1995; Yancey et al., 2006). These considerations can be directly applied to recruitment and retention strategies, study design and set up, approach to dissemination of results, and efforts to incorporate cultural adaptations in future studies. First, community-based participatory research was noted by numerous studies to be an ideal standard to uphold when working with racial/ethnic minority populations. Partnering with a community-based organization or ensuring known members of the community are in shared positions of power within the research team increases trust in the purpose and conduct of the research study. Second, evaluating and meeting the information needs of participants is a practical and important step, not only for obtaining informed consent, but also to increase comfort and likelihood of participating in the study. Informing potential participants about the purpose of the study, measures taken to ensure privacy and confidentiality, and when and how donated samples would be used in future research might appease the most common information needs of participants. Third, incentivizing study participation or ensuring benefits from research are distributed back to participants or their community was repeatedly noted to be important to participants, especially for precision medicine research studies that are unable to return individual genetic test results. Although many participants might be motivated by an altruistic desire to contribute to research endeavors, direct benefits and incentives remain a practical facilitator to participation particularly for communities that might be disadvantaged or less likely to participate in research due to logistical constraints. Fourth, for studies targeting a particular minority community, researchers should put forth effort to evaluate the cultural facilitators and barriers specific to the target community in order to better understand how to implement modifications in study design that would support and respect these cultural preferences. For example, researchers could consider allowing biospecimens other than blood for communities that are averse to donating blood for cultural reasons, as this might be a major drawback to participation for the community and would only require simple modifications for the research study. Without engaging the community through collaborations with community-based organizations or by ensuring the research team includes trusted members of the community
who are involved in the oversight of study design, these cultural preferences might not be revealed and participation rates might be negatively impacted. Culturally competent research practices may be one explanation for the high rates of participation in the genetic research studies that recruited only racial/ethnic minority populations as described here. However, this approach may not be feasible for studies that attempt to recruit a diverse range of participants with many different cultures. Lastly, this analysis of literature exposed the urgent need for better demographic reporting in research studies, initiation of research on other minority populations as well as individuals who are multiracial, and a renewed focus on the interpersonal and policy levels of influenced as defined by the Socio-Ecological Model when designing a precision medicine research study.

This systematic review revealed high interest in genetic research among all racial/ethnic populations included in the synthesized literature, which might dispute the conception that individuals from minority populations are much less willing to participate in genetic testing or research. While participants expressed specific concerns and preferences for study design and conduct, there is a general recognition of the value and benefits of precision medicine research in the public. These findings expand upon prior research by summarizing additional factors that enable or prohibit participation in genetic research beyond simply medical mistrust and characterize various cultural considerations that should be considered when working with specific populations. Results from this systematic review could be applied to future genetic research studies in order to enhance participation of diverse populations and ultimately ensure that results from precision medicine research are applicable to individuals of all racial and ethnic backgrounds.

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