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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 general 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 genetic-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 from 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 Reviews and Meta-Analysis (PRISMA) guidelines and Cochrane guidelines to retrieve articles relating to minority groups' and majority groups' attitudes toward precision medicine research. Studies were limited to those that were conducted in the United States to control for the effect of different healthcare systems, variations in legal protections for genetic testing and research, and sociocultural differences among various populations outside of the United States. Precision medicine research was defined as research involving precision or personalized medicine, genomic- and genetic-based medicine, research use of DNA, or genetic testing that was specifically performed in a research setting. Primary outcomes were defined as the following: study participants' views, attitudes, beliefs, perspectives, opinions, knowledge, understanding, willingness, and/or likelihood of participating in precision medicine research. Minority groups were defined as Black, African American, African, Hispanic, Latino/a, Asian, Asian American, South Asian, Asian Indian, Native American, American Indian, Alaskan Native, Native Hawaiian, Pacific Islander, immigrant, refugee, mixed race, mixed ancestry, bi-racial, multiracial, and/or interracial participants. Majority groups were defined as Whites, Caucasians, and/or participants of Northern European descent.

Studies were excluded from analysis if they met any of the following criteria: not written in English language; not based in the United States; published before 2005; animal or in vitro studies; not original research studies (case reports, review articles, meta-analyses, commentaries, conference proceedings, abstract-only); participants who were not a member of the general public (such as healthcare providers); abstracts explicitly stating >90% of study participants were from majority groups; studies of direct-to-consumer or employment-related genetic testing; studies in which the majority of outcome measures were associated with genetic counseling rather than genetic testing. Studies were limited to the 2005–2018 timeframe due to the growing initiatives that began in 2005 to increase diversity in genetic research (FDA, 2005, 2013). The decision to exclude studies with sample populations of more than 90% White participants was implemented to avoid including findings that may too heavily represent majority group opinions.

2.3 | 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

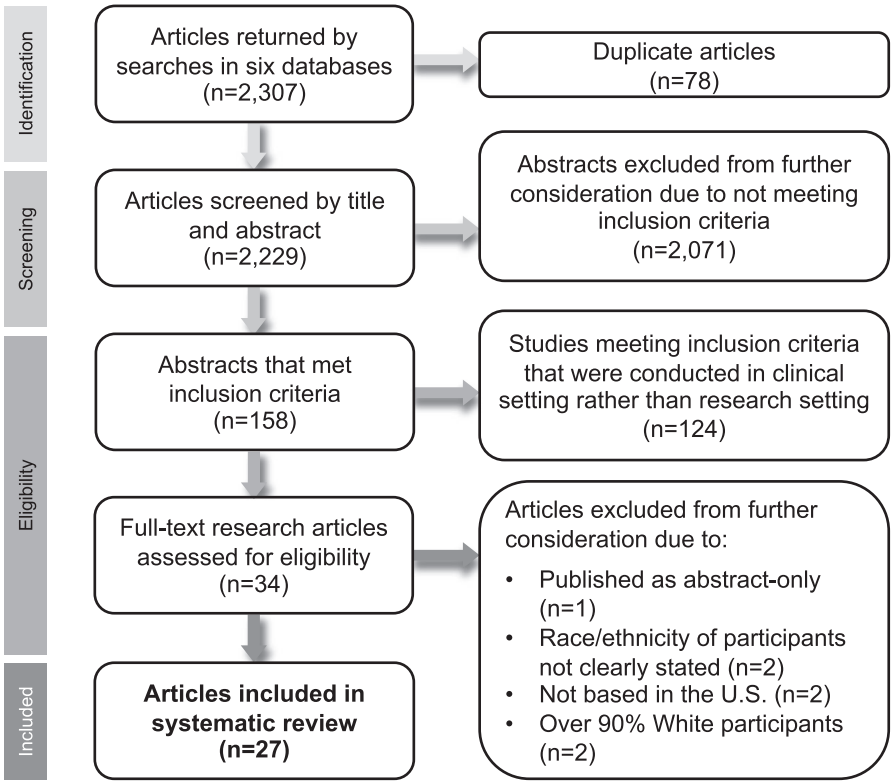

FIGURE 1 Flowchart of systematic review process. Visual representation of the process of selecting the 27 publications included in this systematic review from the 2,307 abstracts returned by the literature search

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; (c) practical considerations that facilitate 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

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	
				Subtheme A: Motivations	Subtheme B: Willingness
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" ($n = 55$)	–	–	• 73% of women consented for unrestricted use of their samples in future genetic studies
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 ($n = 64$)	• Knowledge of Alzheimer's disease and genetic testing was lower in African Americans than Whites** • White participants estimated a higher personal risk of Alzheimer's disease than African Americans and were more concerned about developing the disease than African Americans*	• Reasons for seeking genetic testing included seeking information about treatments or prevention, contributing to research, and arranging personal affairs and long-term care (equally endorsed by both Whites and African Americans)	–
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" ($n = 138$)	–	–	• Less than 1% of all participants had purchased a direct-to-consumer testing kit before the study

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.

3.4.1 | Subtheme A: Motivations for participation

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

Subtheme C: Predictors	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
• Hispanic women had lowest rates of consent for future use of their sample (68%; OR = 0.4)* compared with White women (76%) • African Americans were less likely to agree to subsequent use of their samples as well (OR = 0.6)* • African Americans and Hispanics were most likely to prefer to discard samples after initial study (20% and 28%, respectively)**	• 7% of women requested that investigators first ask permission for use of their sample in future genetics studies (not unrestricted access)	–	–
• African Americans more frequently endorsed confirming feelings of already developing Alzheimer's disease as a reason to test* • White participants were more likely to endorse concerns about test results affecting insurance as a reason not to test* • African Americans were more likely to endorse lack of cure or prevention for Alzheimer's disease as a reason not to test*	–	• A small proportion (26%) of all participants endorsed reasons not to pursue testing, which included concerns about results affecting insurance and lack of a cure or prevention for Alzheimer's disease	–
• 57% of participants favored more federal spending on genetic research; Whites were less likely than Latinos, African Americans, and "other race" to favor more federal funding for genetic research (55% vs. 64%, 63%, 59%, respectively)* • Most participants view genetic nondiscrimination laws as important (82%); Latinos were less likely to view genetic nondiscrimination laws as important compared to Whites (80% vs. 83%**, respectively)	• Majority of respondents (65%) thought clinicians should be involved in explaining direct-to-consumer test results	–	–

(Continues)

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, Vadaparampil, 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.

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
Bloss et al. (2018)	**Design:** Quantitative; cross-sectional online survey **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.	Whites (n = 85,952), Asian Americans and/or Pacific Islanders (n = 9,234), African Americans (n = 4,973), Native Americans (n = 561), "other" (n = 9,407)	• 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)	–	–
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)	• 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%)	–

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

Subtheme C: Predictors	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
• Hispanics**, Asian Americans or Pacific Islanders*, African Americans**, and "other race"** were less likely than Whites to respond to a survey about a hypothetic precision medicine research study (4% all groups vs. 7% Whites) • Asian Americans and Pacific Islanders were the only ethnic group who were significantly less likely to indicate interest in participating in the hypothetical precision medicine research study* • Factors that predicted interest in study participation included more positive beliefs about the value of research, higher levels of precision medicine literacy, placing less importance on controlling one's personal information, and willingness to share more types of personal health data** • Factors that predicted lack of interest in study participation included concerns about data privacy, control, and ownership, desire for control over personal information, and less favorable views about the value of genetic research**	–	–	–
• 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**	–	• 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

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biospecimen collection for research ($n = 8$; 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), and there were no substantial differences between the two types of studies. Approximately half of the research scenarios in which these high consent rates were found involved consent for unrestricted access to participants' samples and health information for future use by other researchers (Aagaard-Tillery et al., 2006; Cox et al., 2007; Culhane-Pera et al., 2017; Nodora et al., 2016; Pettey et al., 2015; Sanderson et al., 2017; Sheppard et al., 2018).

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
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	–
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

Subtheme C: Predictors	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
–	• 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	• 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	• 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 benefitting from the study if not receiving individual results back	–

(Continues)

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
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 p articipants 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 testin g even if no treatment was available

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

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 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** • 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*	–	–	–
–	• African American participants would be interested in testing only when the information obtained would be provided back to individual participants • All groups suggested that providers should avoid medical jargon and technical terminology when consenting, and to establish alertness and orientation in potential participants • Participants thought providers should emphasize the voluntary nature of consent for hospitalized older adults who might not perceive consent as voluntary	• Barriers to testing included not wanting information about personal genetic susceptibility, concerns for disrupting family relationships, and concerns about insurance and employer discrimination • Some participants lacked confidence in the interpretation and validity of genetic test results	• 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 • Participants were apprehensive that passing along information from genetic testing to family would cause illness or shame
• (*Null*) There were no significant differences between African American and White participants in their desire to know results from testing	–	• Participants cited worries that information could hurt them and not being able to improve their health as reasons not to test or know results from testing	–

(Continues)

(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	
				Subtheme A: Motivations	Subtheme B: Willingness
Halbert et al. (2006)	**Design:** Quantitative; cross-sectional structured telephone interviews **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	African Americans ($n = 128$)	–	• 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
Halbert et al. (2016)	**Design:** Quantitative; cross-sectional telephone survey **Goals:** To assess the willingness of African Americans to participate in a clinical study for precision medicine and to identify variables that have a significant independent association with participation.	African Americans ($n = 510$)	–	• 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%)	• 31% of participants reported being willing to participate in a government-sponsored study that involved providing a cheek swab which could be shared with other researchers and that the participants would not receive any results from
Hensley Alford et al. (2011)	**Design:** Quantitative; prospective observational study (online and in-person survey and consent process) **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	African Americans ($n = 3,740$), Whites ($n = 2,608$)	–	–	• Overall rates of participation in testing were 30% among African Americans and 55% among White participants**
Hooper et al. (2013)	**Design:** Quantitative; cross-sectional in-person survey **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.	Hispanics ($n = 26$), Whites ($n = 8$) *10 of 26 Hispanic participants were living in Mexico*	–	• 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)** • Participants who reported fewer concerns about the limitations and risks of research were more likely to be willing to participate (OR = 0.90)**	–	• 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 • 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* • 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	• Facilitators included being given free healthcare services and the study assessing a health condition the individual was worried about • 45% of respondents reported more participation facilitators than barriers, 9% had an equal number of barriers and facilitators, and 46% reported more participation barriers	• Negative expectations about participating in researched 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%) • 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%)	• 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 • Barrier to participation included difficultly getting to where the study was being conducted (63%) • 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 complete the baseline invitation survey about personalized genomics research (first step in study) compared with Whites (33% vs. 36%; OR = 0.88)* • African Americans were less likely to visit the Web site for more information (second step) than Whites (26% vs. 40%; OR = 0.52)** • 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	–	–	–
–	–	• 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 • The number of participants interested in undergoing genetic testing for a research study decreased as the potential risks and complications of the study increased	• English-speaking participants more frequently endorsed a willingness to participate in research trials with higher risks compared with Spanish-speaking participants

(Continues)

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
Hull et al. (2008)	**Design:** Mixed-methods telephone interviews (quantitative and qualitative data) **Goals:** To examine patients' attitudes and preferences regarding use of anonymous and identifiable clinical samples for genetic research	Whites (76%), African Americans (16%), Asian Americans (2%), Native Americans (2%), "other" (4%) *Reported separately:* Hispanic (5%), Not Hispanic (95%) $N = 1{,}193$ total	• 90% of participants had heard at least something about genetic research; 27% had heard "a lot" about genetic research	• 90% of participants reported feeling somewhat or very positive toward genetic research • Reasons for wanting to be notified about research being done included curiosity, knowing they were making a contribution, and patients' rights to know	• Most respondents indicated they would grant permission for their blood samples to be used in research if asked, whether samples were donated anonymously (86%) or were identifiable (84%)
Jazwinski et al. (2013)	**Design:** Quantitative; post hoc analysis of a larger study **Goals:** To characterize groups of patients who accepted or declined pharmaco-genomic testing as part of a larger treatment study on hepatitis C	Whites ($n = 2{,}096$), African Americans ($n = 547$), Hispanics ($n = 211$), Asian Americans ($n = 51$), "other" ($n = 44$)	–	–	• Consent rates for participation in research did not differ according to ethnicity, with similar rates found in Whites (58%), African Americans (54%), and Hispanic participants (57%); consent rates were nonsignificantly lower among Asian American participants (41%)

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	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
• Participants 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)*	• 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	• Concerns about the research topic and concerns about confidentiality and privacy drove participants' desire to know about research being done with their donated sample	• Most participants trusted medical researchers somewhat (56%) or completely (30%)
• (*Null*) Patients who agreed to participate had similar demographic factors, medical comorbidities, and treatment outcomes compared with those who did not provide consent	–	–	–

(Continues)

(n = 4; Cox et al., 2007; Freedman et al., 2013; Jazwinski et al., 2013; Sheppard et al., 2018). Similarly, the findings were conflicting regarding whether higher mistrust in researchers and healthcare systems was a negative predictor of participation (Halbert et al., 2016; Sanderson et al., 2017) or did not correlate with willingness to participate (Sheppard et al., 2018). Higher levels of genetics knowledge and precision medicine literacy were found to be positively associated with willingness to participate in two studies (Bloss et al., 2018; Kinney et al., 2006), while Sheppard et al. reported that consent for research did not vary according to level of healthcare literacy (Sheppard et al., 2018). Two studies reported that greater concerns about data privacy, control, and ownership were associated with decreased likelihood of participation (Bloss et al., 2018; Sanderson et al., 2017), while a study by Halbert et al. did not uphold this finding (Halbert et al., 2016). Additionally, two publications reported a higher willingness to participate in individuals who were less religious (Sanderson et al., 2017; Sheppard et al., 2018), while another study did not support the association of religiosity with lower participation rates (Kinney et al., 2006).

There were clear associations surrounding participants' preferences for research communication practices and the use

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
Jenkins et al. (2011)	**Design:** Qualitative; in-person focus group interviews **Goals:** To understand motivations and barriers to participation in studies that use DNA collection.	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 **Goals:** To examine predictors of *BRCA1* testing decisions, as well as barriers and facilitators to participation, in male and female members of an African American kindred with a *BRCA1* mutation	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

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

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 • Respondents noted that reminder telephone calls had positive effects on their participation • Participants suggested researchers develop materials targeting fathers or including advice for mothers on how to encourage the father to participate • Responses were mixed regarding whether inclusion of a short video or Web site with additional information would facilitate sample collection	• 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 • 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 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 who did not return a specimen stated that they preferred to receive individual results	• African American participants reported their child's father expressing concern about how their biologic samples would be used by the government • Participants expressed personal concerns about the government using their biologic material
• 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)* • (*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	–	• Reasons for declining to participate included lack of interest (54%), personal problems (6%), and negative test results in other relatives (4%) • 53% of participants thought their regular healthcare provider did not have adequate knowledge to provide genetics services and lacked education and training	• 18% of participants indicated that they would not have been tested had it not been accessible and available through this study; they also reported that higher out-of-pocket testing costs reduced interest in testing • Negative experiences with prior participation in genetic research were cited as a reason not to participate by 10% of respondents • Time constraints (12%) and study logistics (8%) were cited as reason for declining to participate • Reasons for not getting clinical genetic testing prior to the study included lack of access to information, lack of knowledge about the test, and lack of knowledge about where to go for genetic counseling and testing

(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

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
Lakes et al. (2013)	**Design:** Qualitative; in-person focus group interviews **Goals:** To study maternal preferences for the return of their child's genetic results and to describe the experiences, perceptions, attitudes, and values that are considered when individuals from different racial and cultural backgrounds consider participating in genetic research	Whites (49%), Asian Americans (21%), Pacific Islanders (6%), Iranians (4%), African American and White (2%), Native American/ Alaskan and White (2%), no response or "other" (17%) *Reported separately:* Hispanic (28%), not Hispanic (72%) $N = 50$ total	–	• A commonly cited benefit of participating in genetic research and receiving results was to obtain results that were relevant to a known genetic risk in the family • Mothers differentiated between receiving results for themselves and results for their babies; they were more likely to request results for themselves	–

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; Rew et al., 2010; Sanderson et al., 2017; 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), 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,

Subtheme C: Predictors	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
–	• Preferences and expectations about return of results depended on context of the disease, whether treatments were available, personal characteristics such as anxiety or desire for control, timing of results disclosure, and relation to family history of disease • Latina participants saw return of individual results as a significant incentive to participate in a genetic study, and noted that having a family history of a disorder might increase participation • Participants desired an interpersonal, dynamic, flexible process that accommodated individual preferences and contextual differences for returning results • When results were returned that were perceived as negative, Latina participants expected researchers to facilitate an intervention (not just make a referral) • Latina mothers wanted more information about whether personal actions could help prevent a particular disease before deciding to receive genetic results for a child • Some participants wanted to know about all possible studies that would be done with their baby's sample and the security measures in place to avoid misuse of samples	• Perceived barriers to participation included potential emotional harms of receiving results, anticipated negative effects on the parent–child relationship or quality of life, and not receiving individual results for some participants	• Latinas indicated that receiving genetic results during pregnancy could be traumatic if the individual belongs to a culture where terminating a pregnancy is not considered an option

(Continues)

2009; Pettey et al., 2015; Simon et al., 2017). 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	
				Subtheme A: Motivations	Subtheme B: Willingness
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 destigmatizing 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)

3.6 | Theme 4: Concerns and barriers to participation in genetic testing and research

Concerns about participation, reasons not to test or receive results from testing, and factors that presented barriers to participation in research were assessed by 18 publications (Akinleye et al., 2011; Buseh et al., 2014, 2012; Culhane-Pera et al., 2017; Frazier et al., 2006; Freedman et al., 2013; Halbert et al., 2006, 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; Simon et al., 2017). The most commonly cited reasons not to participate in genetic testing or research included privacy and confidentiality concerns ($n = 7$; Buseh et al., 2012; Halbert et al., 2016; Hull et al., 2008; Murphy & Thompson, 2009; Pettey et al., 2015;

Subtheme C: Predictors	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
-	• Facilitators to participation included receiving direct benefits, such as treatment, education, assessment, or other form of research-related intervention; monetary compensation was mentioned in all groups • Desirability of following up with participants (e.g., following up about results) as a way of making their participation more meaningful • Participants also favored hospitable accommodations at research sites (food, activities while waiting) • The preferred method of being alerted about ongoing research studies was through word of mouth	• Concerns about potentially harmful or unpleasant study procedures and unwanted adverse effects were barriers to participation • Participants cited a fear of the unknown as a barrier to participation for some people • Concerns about confidentiality and privacy regarding family history of psychiatric disorders were also prevalent	• 25% of participants felt that minority communities are uneducated about genetics • Participants noted general feelings of stigmatization surrounding psychiatric disorders, and concerns about inability to involve family in research due to stigmatization of mental illness in Black community • Some participants doubted that information garnered from research findings would be beneficial to Black people in all cases • Perceived drawbacks to participating also included past negative experiences affecting current willingness and worries about unethical experimentation • One participant cited race-based distrust in medical research as a reason not to participate • Lack of awareness about ongoing genetic research studies was cited as a reason most participants had never participated previously
• (*Null*) Demographic variables of participants did not vary between the two consenter groups (physician vs. research assistant)	–	–	–

(Continues)

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; Sanderson 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

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
Pettey et al. (2015)	**Design:** Qualitative; in-person semi-structured individual interviews **Goals:** To examine the feasibility of developing pedigrees and to explore perceptions of family history and genetic research among African Americans with hypertension	African Americans ($n = 29$)	• Participants' knowledge of family history of disease included good and bad behaviors associated with disease, problems due to disease, and barriers to obtaining health care • 90% of participants were able to report sufficient detail about their family history of disease to generate a pedigree	• Reasons to participate in research included wanting to help others, finding a cure for hypertension, learning more, and finding the right medicine for the right person • Participants said their strong family history of disease motivated them to take better care of their health, but this family history had no influence on current actions	• 83% of participants stated they would participate in a future genetic study and would be willing to provide a DNA sample
Rew et al. (2010)	**Design:** Qualitative; semi-structured individual interviews **Goals:** To determine levels of knowledge and approaches to decision-making regarding genetics and genetic testing in adolescents and their parents	Whites ($n = 16$), Hispanics ($n = 8$), Asian Americans ($n = 5$), African Americans ($n = 4$)	• Most participants in all groups had heard of genetic testing, but younger adolescents did not have accurate knowledge; parents' knowledge was somewhat more complete and older adolescents were most knowledgeable • The majority of older adolescents had accurate knowledge of the Human Genome Project; younger adolescents and parents' knowledge was very limited • Primacy sources of information about genetics included the Internet and doctors; almost half of younger adolescents would use their parents as a source of information when making decisions about testing	• Participants thought genetic testing would be useful to learn about future diseases in order to take actions to prevent or prepare for them	–

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 • One participant stated they would only participate if the results would be given back to individuals after the study	• Concerns about participating included concerns about the test being painful and not being sure that a genetic study of hypertension would be helpful • Concerns about privacy included wanting the sample to only be used for the particular study consented for	• Culture influenced family teaching about disease and included home remedies • 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	–

(Continues)

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;

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
Sanderson et al. (2017)	**Design:** Quantitative; randomized three-arm mailed survey design **Goals:** To assess willingness to participate in a biobank using different consent and data sharing models and to examine perceived benefits, concerns, and information needs regarding participation in biobank research	Whites (51%), Asian Americans (17%), African Americans (12%), Native American or Alaska Natives (5%), Native Hawaiian or Pacific Islanders (1%), "other" (10%), more than one race (3%) *Reported separately:* Hispanic (18%), not Hispanic (82%) $N = 13{,}000$ total	–	• Perceived benefits of participating included helping future generations (84%), leading to better medical treatments (83%), helping doctors take better care of patients (78%), helping their family (65%), helping themselves personally (44%)	• 66% of participants would be willing to participate in the biobank described to them
Sheppard et al. (2018)	**Design:** Quantitative; telephone survey and mailed specimen kit **Goals:** To understand sociocultural, health care, and clinical factors that impact women's participation in genetic research in Black and White breast cancer survivors	Whites ($n = 391$), African Americans ($n = 155$), Asian Americans and "other subgroups" ($n = 23$)	–	• The most common reason for providing consent was altruism and wanting to help further research	• 70% of participants returned saliva kits for biobanking for research

Jenkins et al., 2011; Kinney et al., 2006; Lakes et al., 2013; Murphy & Thompson, 2009; Pettey et al., 2015; Sanderson et al., 2017; Sheppard et al., 2018; Simon et al., 2017).

The majority of participants' organizational- and community-influenced considerations about research constituted barriers to participation. Overall, in this selection

Subtheme C: Predictors	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
• 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*	• 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%)	• 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	• 64% agreed that they trusted their healthcare system, and 61% agreed that they trusted medical researchers
• (*Null*) Provision of specimens did not vary according to race of the participants • Women with earlier stage breast cancer* and those with higher functional well-being* were more likely to provide specimens for research • Participants who were more satisfied with their provider**, reported higher ratings of patient–provider communication*, and had higher satisfaction with the time providers spent with them** were more likely to provide biospecimens for research • Participants reporting greater access to health care were more likely to provide biospecimens** • Women with lower ratings of religiosity were more willing to provide a specimen for research** • (*Null*) Perceived healthcare discrimination, medical mistrust, and healthcare literacy did not differ between participants who provided biospecimens and those who did not	–	–	–

(Continues)

of articles, the barriers included concerns about being viewed negatively or ruining participants' reputations in the community if test results were perceived as negative, apprehension about sharing health information in cultures where this is discouraged or stigmatized, cultural beliefs that prevented participation such as the desire for the body

TABLE 1 (Continued)

Study	Design and study goals	Population	THEME 1: Knowledge and understanding of genetics	THEME 2: Engagement and participation in research	
				Subtheme A: Motivations	Subtheme B: Willingness
Simon et al. (2017)	**Design:** Qualitative; semi-structured focus group interviews **Goals:** To describe attitudes toward, and barriers and facilitators of, participation in biospecimen research among Chinese older women	Chinese women ($n = 47$)	–	• Benefits of biospecimen research identified by participants included improving research developments for drugs and disease, enabling early diagnosis and treatment, and benefitting future generations and others • Participants held predominantly positive attitudes toward biospecimen research overall	–

Note: All quantitative findings were significant (*$p \leq .05$ and **$p \leq .01$) unless otherwise stated. Odds ratio (OR).

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-Pera 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; Bloss 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; Bloss 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; Bloss et al., 2018; Culhane-Pera 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-Pera 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, Bloss et al. reported that Asian

Subtheme C: Predictors	THEME 3: Practical considerations that facilitate participation	THEME 4: Concerns and barriers to participation	THEME 5: Cultural- and community-specific considerations
–	• Facilitator to participation involved allowing alternate specimen types including donation of hair or nail biospecimen instead of requiring blood • Compensation and receiving reports or other health service benefits were facilitators to participation • Trust building was important when considering whether to participate; it was suggested that word of mouth would leverage this trust in the community • Participants suggested increasing education to promote awareness of biospecimen research	• Perceived barriers to participation included negative effects of testing on physical health, concerns about privacy, opinions that research may not be useful to them personally due to research timelines, and lack of reporting back to individual participants about results • Various impediments related to old age were cited, including perspectives that older adults are not useful or are too poor of health to be used in research	• Participants identified benefits of biospecimen research specific to the Chinese community, noting there were differences between Chinese and Whites; they thought that research would benefit aging minority groups such as Chinese • Perspective of keeping the body whole (blood donation violating this belief) as a barrier to participation • Barrier to participation involved being worried about privacy and maintaining a good reputation in the community which could be lost if harmful info is found

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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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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