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Genetic Testing and Other Healthcare Use by Black and White Individuals in a Genomic Sequencing Study

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Racial disparities · Genetic testing · Early adopters · Healthcare use

Abstract

Introduction: Early adopters play a critical role in the diffusion of medical innovations by spreading awareness, increasing acceptability, and driving demand. Understanding the role of race in the context of other characteristics of potential early adopters can shed light on disparities seen in the early implementation of genomic medicine. We aimed to understand the association between self-identified race and individual experience with genetic testing outside of the research context. ***Methods:*** We assessed factors associated with the odds of having ever received genetic testing prior to enrollment in a genomic sequencing study among 674 self-identified white and 407 self-identified African, African American, or Afro-Caribbean ("Black") individuals. ***Results:*** Controlling for individual determinants of healthcare use (demographics, personality traits, knowledge and attitudes, and health status), identifying as Black was associated with lower odds of prior genetic testing (OR = 0.43, 95% CI [0.27–0.68], $p < 0.001$). In contrast, self-identified race was not associated with the use of non-genetic clinical screening tests (e.g., echocardiogram, colonoscopy). Black and white individuals were similar on self-reported personality traits tied to early adoption but differed by sociodemographic and resource facilitators of early adoption. ***Conclusion:*** Persistent racial disparities among early adopters may represent especially-entrenched disparities in access to and knowledge of genomic technologies in clinical settings.

Introduction

Genetic medicine has the potential to transform individual lives and improve public health through prevention, early diagnosis, and targeted treatment. The field is rapidly advancing; indeed, about ten new genetic tests

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enter the market daily (though coverage and reimbursement vary) [1]. Yet many people who meet established clinical criteria and stand to benefit do not receive genetic testing. Underutilization is especially pronounced among minoritized groups, including Black or African Americans. In the USA, patients who are racialized as Black have lower rates of referral for genetic evaluation, genetic counseling, testing, and definitive diagnosis compared to non-Hispanic white patients. Such inequalities have been reported across applications including prenatal genetic screening, rare disease diagnosis, and identification of hereditary cancer syndromes [2–4]. Racial inequalities in genetic testing may contribute to and exacerbate health disparities [5, 6]. Black patients who do enroll in research studies or navigate access to clinical genetic testing can provide insight into how innovations in genetic medicine may diffuse in minoritized communities and reveal potential targets for interventions aimed at reducing disparities.

Innovators and early adopters are individuals who embrace new technologies before the majority of the population because of their excitement and view that the advantages of innovation outweigh its costs [7]. First characterized by Everett Rogers in his 1962 book Diffusion of Innovations, early adopters play a critical role in the early stages of technology adoption and often influence the diffusion and success of innovations because they take on some early risks and set trends that influence more widespread adoption [8, 9]. Groups who adopt innovations later rely on the judgments and experiences of early adopters, as well as social pressure to adopt. Much of the healthcare innovation diffusion literature has focused on clinician behavior change [10, 11], but innovation diffusion cannot happen without adoption by payers, health systems, clinicians, and patients [7]. Patients as early adopters in genomic research and medicine are important because of their role in shaping clinical implementation and their influence on other people in their social networks. Additional focus on research participant and patient innovation adoption is important.

Across technology sectors and studies, the propensity for early adoption has been explained by personality, behavioral, sociodemographic, and resource factors [10]. The first two categories (personality and behaviors) include intrinsic traits such as optimism, resilience, and risk tolerance that make some people more eager to try newer, potentially beneficial technologies. Factors in the final two categories (individual sociodemographics and resources) have greater dependence on extrinsic structural or relational dynamics and include educational attainment, income, experience, and knowledgeable social networks that enable access to information and innovation [10, 12]. Some studies have found that early adopters are more likely to identify as white, but there is limited research on the role of racial identity in healthcare technology adoption in the context of other factors. One survey study showed similar openness to hypothetical non-medical technology innovation among Black and white veterans but lower openness to medical innovation among Black veterans when controlling for health status and other demographic factors [13].

Participants in genomic medicine research have been characterized as early adopters because of their involvement in testing novel clinical services, and they exhibit many of the qualities typical of early adopters [14]. Genetic testing is not new; however, it is still underutilized in many clinically indicated settings, and patient awareness of its appropriate use lags. Genomic research participants score highly on personality traits associated with early adopters: extraversion, optimism, resilience, and risk tolerance [15, 16]. They have also been predominantly white, highly educated, and high-income earners [15, 16]. We expect that genomic research participants would be similar to early adopters of genomic medicine outside the research context because of their openness to and interest in genomic medicine innovation.

Individuals may exhibit some characteristics of early adopters (e.g., optimism and risk tolerance) and not others (e.g., social networks enabling exposure to new technology), which would influence their position along the innovation adoption spectrum. In genomic medicine studies that specifically recruit non-white participants, the intersection of self-identified race with research participation complicates the picture of the typical early adopter. Most studies have found small or negligible differences in personality traits by racial group [17, 18]. Similar to other social and behavioral traits that are partially determined by genetics, personality traits associated with early adoption are likely to vary more within racial groups than across groups [19, 20]. On the other hand, sociodemographic and resource factors vary substantially across socially defined racial groups in the USA. Because of highly entrenched inequalities driven by historical bias and long-standing racial inequity, minoritized groups experience substantial disadvantages in income, education, access to healthcare, and opportunities to engage with privileged social networks necessary for accessing innovative interventions relative to majority groups [21]. Research on participants' attitudes, characteristics, and past experiences can give insights into the potential role of race and non-racial factors in genomic medicine use among those at the forefront of technology adoption.

The purpose of this study was to determine the potential association between self-identified race and prior genetic testing among individuals in a large, longitudinal exome sequencing study. We hypothesized that even among genomic research participants, identifying as Black would still be associated with a lower likelihood of being early adopters of genetic testing outside of the research context. The basis of our hypothesis is that despite the stability and predicted similarity along early adopter personality traits, Black participants face barriers to early adoption of medical innovation due to socio-demographic and resource factors. Though genomic medicine is not new, it is not fully routinized and is susceptible to lingering effects of incomplete technology diffusion. We, therefore, further hypothesized that racial inequalities in relatively innovative genetic testing would be greater than racial inequalities in more established healthcare screening (e.g., colonoscopy), demonstrating a specific racial inequality in innovation diffusion distinct from overall healthcare disparities.

Materials and Methods

Population

We analyzed baseline survey data from 674 self-identified white and 407 self-identified African, African American, or Afro-Caribbean individuals in ClinSeq® – a longitudinal cohort study designed to investigate the implementation of large-scale clinical exome sequencing for clinical research, including scientific potential, consent for secondary uses, and reporting of research results to individuals [22]. The study was open to older adults (median age 60) in the greater Washington, DC area. The first round of recruitment enrolled 1,001 individuals in 2007–2013, of whom 85% self-identified as non-Hispanic white. The first round of recruitment included a focus on cardiovascular health, with a target of 25% of participants meeting diagnostic criteria for coronary artery disease. To increase the racial diversity of the sample, a second round of targeted recruitment in 2012–2017 enrolled 467 individuals who self-identified as African, African American, or Afro-Caribbean (hereafter "Black"). Cardiovascular disease phenotypes were not targeted in the second cohort, resulting in a much lower prevalence of coronary artery disease in the second cohort. The study protocol, recruitment, surveys, cohort makeup, and differences across the cohorts have been described in more detail elsewhere [14, 16, 22]. Individuals completed a baseline survey including questions about personality traits, attitudes, knowledge, and healthcare use (as well as other measures not discussed in this paper). Individuals without available baseline survey data (n = 338) or who reported their race as other than white or African, African American, or Afro-Caribbean (n = 49) were excluded from this analysis. All procedures, including recruitment, the consent process, data collection, and data management were conducted following federal regulations and under the oversight of the National Human Genome Research Institute intramural IRB. Written informed consent was obtained from all individuals as required by the IRB. De-identified data were provided for this analysis.

Dependent and Independent Variables

Measures were scored as described in prior ClinSeq® publications. If an individual had missing data on one or more items within a multi-item measure, the measure was determined based on the mean of the remaining items.

The binary outcome measure – prior genetic testing – was solicited with the following question: "Have you ever received a genetic test result? (Yes/No)," without restricting the purpose of genetic testing (e.g., diagnostic, predictive, reproductive, ancestry). The use of non-genetic clinical screening tests was assessed by asking individuals how recently they had undergone 16 different clinical tests (eye examination, echocardiogram, colonoscopy, etc.). Response options were never or N/A, >10 years ago, past 10 years, past 5 years, past 2 years, past year. Scores across the 16 items were averaged (possible range of 0–5).

We identified potential individual-level drivers of healthcare use based on studies of early adopters, prior studies of genetic medicine use, and the Andersen Behavioral Model of Health Services Use [23]. We expected prior genetic testing and non-genetic clinical screening would be associated with basic demographic factors (self-reported white race, older age, and female gender), social advantage (higher educational attainment and higher household income), personality characteristics (greater neuroticism, lower information avoidance, lower tolerance of uncertainty, and greater self-affirmations), knowledge factors (higher subjective numeracy and greater knowledge of genetics), beliefs about genetics (more positive attitudes about genetic test results, greater perceived value of genetics, intentions to learn test results when offered), and health status (worse perceived overall health, coronary artery disease diagnosis, and greater perceived risk of hereditary disease).

Educational attainment was scored as high school or below, some colleges or technical schools, college graduate, or post-graduate. Annual household income was dichotomized above or below $100,000. The Big Five personality traits (extraversion, agreeableness, conscientiousness, neuroticism, and openness): mean of 8–10 items scored from 1 to 5 [16]. Information avoidance: mean of six items scored from 1 to 7 [24]. Tolerance for uncertainty: mean of seven items scored from 1 to 5 – higher scores represented less tolerance for uncertainty [16]. Spontaneous self-affirmation: mean of two items scored from 1 to 5 [24]. Subjective numeracy: mean of three items scored from 1 to 6 [25]. Three knowledge of genetics subscales based on ten total items: benefits of sequencing scored from 0 to 10, limitations of sequencing scored from 0 to 10, and hereditary concepts scored from 0 to 8 [26].

Variables related to attitudes and beliefs about genetics included perceived value of genetics (mean of three items scored from 1 to 5) [27]; attitudes toward genetic testing for preventable or treatable conditions, non-preventable or non-treatable conditions, and reproductive screening (mean of six items for each measure) [28]; and intentions to learn personal test results related to preventable or treatable conditions, non-preventable or non-treatable conditions, and reproductive screening (a single item for each, scored from 1 to 7) [28].

Personal health status included self-perceived global health using the PROMIS score, averaging ten items scored from 1 to 5 [29], cardiovascular disease diagnosis (yes/no), and perceived risk of hereditary disease compared to others (mean of three items scored from 1 to 7) [30].

Statistical Analysis

Analysis was completed using Stata (v17.0). Race-specific sample differences were tested with the median test (median ties split) for ordinal variables and Pearson's χ^2 for categorical variables.

The association between identifying as Black and prior genetic testing was assessed using logistic regression, and the association between identifying as Black and greater use of non-genetic clinical screening was assessed using linear regression. Considering the Institute of Medicine's 2002 definition of racial disparity as a difference in care attributable to anything other than patient preferences and health status [31], model 1 and model 3 do not control for factors related to socioeconomic status and education. Model 2 and model 4 control for these additional factors. Predicted probabilities of prior genetic testing were generated from the logistic regression models using the Stata margins command with the option pwcompare to perform pairwise comparisons of predicted probabilities between Black and white participants. We report p values based on two-tailed tests to allow for the possibility of detecting differences in the opposite direction of our primary hypotheses and to maintain a conservative test for significance at $p < 0.05$.

We ruled out missing higher-order variables or interaction terms. We theorized that the following variables might operate as moderators of the association of race and healthcare use: income, educational attainment, and perceived global health. However, in simplified logistic regressions that included race, one potential moderator, and the interaction of race and the moderator, none of the interaction terms was significantly associated with non-genetic clinical screening. Additionally, the specification test "linktest" showed that there were no statistically predicted higher-order variables or interaction terms missing in any of the models.

We assessed potential problems of multicollinearity through bivariate correlations and mean variance inflation factors (VIFs) for each of the models. The mean VIF for the most restricted model was 1.62 (all other models had a lower mean VIF). The highest correlation values were among the measures of intentions to learn genetic results ($r = 0.67$–0.71). These three variables also had the highest single variable VIFs, 2.49–2.94, below the standard cutoff of VIF >10. We retained all three intention variables because they did not result in problematic VIF values and because they are theoretically distinct and relevant to the health behaviors being modeled.

Results

Preliminary Analyses

Study population characteristics by race have been previously reported and are shown here in Table 1. Due to analytical decisions made for each paper, there are minor differences in sample sizes and reported study population characteristics that do not significantly influence results. As reported previously [14], white individuals were significantly more likely to have sociodemographic and knowledge characteristics we predicted to be associated with preventive medicine use and early adoption of prior genetic testing. Nearly 90% of white individuals had at least a college degree compared to 66% of Black individuals ($\chi^2(3) = 90.74$, $p < 0.001$). 78% of white individuals had annual household incomes over $100,000 compared to 38% of Black individuals ($\chi^2(4) = 183.56$, $p < 0.001$). White individuals had higher subjective numeracy scores (median score 5.33 vs. 5 on a scale from 1 to 7, $\chi^2(2) = 32.20$, $p < 0.001$). White individuals also scored higher on all three knowledge of genetics scores ($p < 0.001$ for knowledge of sequencing limitations and knowledge of hereditary concepts, and $p = 0.007$ for knowledge of sequencing benefits).

Black individuals scored comparably to or higher than white individuals on personality traits and attitudes predictive of early adoption [14, 32, 33]. Black individuals reported more self-affirmation ($p < 0.001$), more positive views of the value of genetic information ($p < 0.001$), and more positive attitudes toward genetic testing for non-preventable or non-treatable conditions ($p = 0.002$). There were no significant differences by race for extraversion, openness, information avoidance, or tolerance of uncertainty. Both Black and white individuals had positive attitudes toward genetics and reported strong intentions to learn about their genetic test results, with median scores ranging from 6.33 to 7 on a scale from 1 to 7 for each attitude or intention variable. White individuals reported a higher perceived risk of genetic disease ($p = 0.026$).

Importantly, the first cohort of mostly white participants was enriched for patients with coronary artery disease (CAD) compared to the later cohort of Black participants. Individuals who had coronary artery disease considered their risk for genetic disease to be elevated (median score 5 on a scale from 1 to 7, compared to median score 4 in people without CAD, $\chi^2(1) = 35.70$, $p < 0.001$). When we controlled for CAD there was no racial difference in the perceived risk of genetic disease. We controlled for CAD in all regression analyses.

Main Analysis 1: Identifying as Black Was Associated with Lower Odds of Prior Genetic Testing

Logistic regression results are reported in Table 2 and Figure 1. Eleven percent of Black individuals reported ever having had a prior genetic test compared to 21% of white individuals ($\chi^2(1) = 18.43$, $p < 0.001$). Controlling for personality, attitudinal, and health-related factors (but not controlling for household income, educational attainment, subjective numeracy,

Table 1. Study population characteristics by self-identified race

	Total (n = 1,081)	White (n = 674)	Black (n = 407)	χ^2	p value
Demographics					
Age (n = 1,081), years	60 (55–65)	62 (58–66)	57 (52–62)	$\chi^2(1) = 59.25$	<0.001
Gender (n = 1,081), n (%)				$\chi^2(1) = 83.19$	<0.001
Male	459 (42.46)	358 (53.12)	101 (24.82)		
Female	622 (57.54)	316 (46.88)	306 (75.18)		
Educational attainment (n = 1,053), n (%)				$\chi^2(3) = 90.74$	<0.001
High school degree or below	49 (4.65)	18 (2.76)	31 (7.71)		
Some college/technical	164 (15.57)	58 (8.91)	106 (26.37)		
College graduate	296 (28.11)	178 (27.34)	118 (29.35)		
Post-graduate	544 (51.66)	397 (60.98)	147 (36.57)		
Household income (n = 1,031), n (%)				$\chi^2(4) = 183.56$	<0.001
<$25,000	40 (3.88)	7 (1.10)	33 (8.38)		
$25,000–$49,000	80 (7.76)	27 (4.24)	53 (13.45)		
$50,000–$74,999	112 (10.86)	34 (5.34)	78 (19.80)		
$75,000–$100,000	153 (14.84)	72 (11.30)	81 (20.56)		
>$100,000	646 (62.66)	497 (78.02)	149 (37.82)		
Personality traits and knowledge (range)					
Big Five: extraversion (1–5) (n = 1,030)	3.50 (3.00–4.13)	3.50 (2.88–4.13)	3.63 (3.13–4.13)	$\chi^2(1) = 3.28$	0.070
Big Five: agreeableness (1–5) (n = 1,028)	4.22 (3.78–4.56)	4.11 (3.67–4.44)	4.33 (4.00–4.67)	$\chi^2(1) = 27.62$	<0.001
Big Five: conscientiousness (1–5) (n = 1,027)	4.11 (3.67–4.56)	4.11 (3.67–4.56)	4.33 (3.78–4.67)	$\chi^2(1) = 13.26$	<0.001
Big Five: neuroticism (1–5) (n = 1,026)	2.25 (1.75–2.75)	2.38 (1.88–2.88)	2.13 (1.75–2.63)	$\chi^2(1) = 19.00$	<0.001
Big Five: openness (1–5) (n = 1,026)	3.90 (3.50–4.30)	3.90 (3.50–4.30)	3.90 (3.50–4.30)	$\chi^2(1) = 0.07$	0.794
Information avoidance (1–7) (n = 1,066)	1.82 (1.00–2.67)	1.83 (1.00–2.80)	1.67 (1.00–2.50)	$\chi^2(1) = 2.12$	0.145
Tolerance for uncertainty (1–5) (n = 1,059)	2.57 (2.00–3.14)	2.57 (2.00–3.14)	2.57 (2.14–3.14)	$\chi^2(1) = 0.04$	0.840
Self-affirmations (1–5) (n = 1,057)	4.00 (3.00–4.00)	3.50 (3.00–4.00)	4.00 (3.50–5.00)	$\chi^2(1) = 70.29$	<0.001
Subjective numeracy (1–7) (n = 1,069)	5.33 (4.67–6.00)	5.33 (4.67–6.00)	5.00 (4.33–5.67)	$\chi^2(1) = 32.20$	<0.001
Knowledge of genetics					
Sequencing limitations subscale (0–10) (n = 1,073)	6.00 (4.00–9.00)	7.00 (5.00–9.00)	5.00 (3.00–7.00)	$\chi^2(1) = 76.56$	<0.001
Sequencing benefits subscale (0–10) (n = 1,070)	5.00 (4.00–7.00)	5.00 (4.00–8.00)	5.00 (4.00–7.00)	$\chi^2(1) = 7.19$	0.007
Heredity concepts subscale (0–10) (n = 1,069)	2.00 (1.00–4.00)	3.00 (1.00–5.00)	2.00 (1.00–3.00)	$\chi^2(1) = 16.95$	<0.001
Attitudes toward genetics (range)					
Perceived value of genetic information (1–5) (n = 1,064)	4.00 (3.67–5.00)	4.00 (3.33–4.67)	4.33 (4.00–5.00)	$\chi^2(1) = 48.02$	<0.001
Attitudes toward genetic testing (1–7) (n = 1,074)					
Preventable/treatable (1–7) (n = 1,066)	7.00 (6.83–7.00)	7.00 (6.83–7.00)	7.00 (6.83–7.00)	$\chi^2(1) = 0.60$	0.439
Non-preventable/non-treatable (1–7) (n = 1,065)	6.50 (5.17–7.00)	6.33 (5.00–7.00)	6.83 (5.50–7.00)	$\chi^2(1) = 9.94$	0.002
Reproductive utility (1–7) (n = 1,069)	7.00 (6.50–7.00)	7.00 (6.50–7.00)	7.00 (6.67–7.00)	$\chi^2(1) = 1.07$	0.301
Intentions to learn genetic results (1–7) (n = 1,065)					
Preventable/treatable (1–7) (n = 1,059)	7.00 (6.00–7.00)	7.00 (6.00–7.00)	7.00 (6.00–7.00)	$\chi^2(1) = 6.51$	0.011
Non-preventable/non-treatable (1–7) (n = 1,056)	7.00 (6.00–7.00)	7.00 (6.00–7.00)	7.00 (6.00–7.00)	$\chi^2(1) = 1.82$	0.177
Reproductive utility (1–7) (n = 1,059)	7.00 (6.00–7.00)	7.00 (6.00–7.00)	7.00 (6.00–7.00)	$\chi^2(1) = 5.26$	0.022
Health and healthcare utilization (range)					
Perceived global health (1–5) (n = 1,065)	4.10 (3.60–4.40)	4.10 (3.70–4.50)	4.00 (3.60–4.30)	$\chi^2(1) = 22.65$	<0.001
Has coronary artery disease (n = 1,081), n (%)	126 (12.58)	128 (18.99)	8 (1.97)	$\chi^2(1) = 66.88$	<0.001
Perceived comparative risk (1–7) (n = 1,057)	4.00 (3.67–5.00)	4.33 (3.67–5.00)	4.00 (3.33–5.00)	$\chi^2(1) = 4.98$	0.026
Non-genetic clinical screening (0–5) (n = 1,072)	2.63 (2.19–3.10)	2.69 (2.25–3.13)	2.56 (2.00–3.00)	$\chi^2(1) = 9.09$	0.003
Had a prior genetic test (n = 1,057), n (%)	183 (17.31)	140 (21.18)	43 (10.86)	$\chi^2(1) = 18.43$	<0.001

Values are median (IQ) or n (%). A portion of these analyses were previously reported. Due to analytical decisions made for each paper, there are minor differences in sample sizes and reported study population characteristics that do not significantly influence results.

and knowledge of genetics), identifying as Black was associated with lower odds of prior genetic testing (model 1, OR = 0.43, 95% CI = [0.27–0.68], $p < 0.001$). Holding all other variables at their means, the predicted probability of prior testing was 11 percentage points lower for Black participants compared to white participants (95% CI = 0.06–0.17).

Controlling for household income, educational attainment, subjective numeracy, and knowledge of genetics, the racial disparity in genetic testing use persisted (model 2, OR = 0.57, 95% CI = [0.35–0.94], $p = 0.028$). Holding all other variables at their means, the predicted probability of prior testing was seven percentage points lower for Black participants compared to white participants (95% CI = 0.01–0.13).

Main Analysis 2: Identifying as Black Was Not Associated with Lower Use of Non-Genetic Clinical Screening Tests

Linear regression results are reported in Table 3 and Figure 2. Without controlling for other factors, Black individuals reported lower use of non-genetic clinical screening (median score 2.56) compared to white individuals (median score 2.69) ($\chi^2(1) = 9.09$, $p = 0.003$). However, there was no significant association between race and non-genetic screening when controlling for age, gender, personality traits, and health status (model 3). Adding genetics-specific factors (attitudes, intentions, and knowledge) and contributors to disparities (educational attainment, income, and subjective numeracy), there was still no association between race and non-genetic screening (model 4). Only when removing coronary artery disease status from the model (data not shown) did identifying as Black appear to be associated with a 0.10-point reduction in healthcare screening score ($\beta = -0.10$, 95% CI = [−0.21 to 0.00], $p = 0.045$). Therefore, in this population, lower rates of non-genetic screening by Black individuals may be due to differences in coronary artery disease prevalence in the first and second rounds of participant recruitment rather than an independent effect of race or racial disparities.

Discussion

We found that identifying as Black was associated with lower odds of genetic testing but not with lower use of non-genetic clinical screening. Furthermore, self-identified Black and non-Hispanic white participants were found to be similar along personality factors but differ along sociodemographic and resource factors. These findings are important and novel for two reasons. First, they highlight a specific racial inequality in genomic medicine even among people with otherwise similar preventive medicine use. Second, they suggest that personality and behavioral characteristics are insufficient for early adoption if sociodemographic and resource factors limit opportunities to use comparatively novel interventions. We found that, where differences existed, Black participants scored higher on personality traits and attitudes associated with early adoption. Having especially strong personality traits of early adopters may be essential for overcoming barriers to research participation.

Multiple factors could contribute to inequalities in the early adoption of genomic medicine compared to the use of more established interventions. Access to any relatively novel medical intervention is subject to greater variation in clinician behavior, patient awareness, and insurance coverage compared to access to well-established interventions [34] – all of which are likely to have an amplified impact on patients facing even minor barriers to care. Black patients are less likely to have stable medical homes with primary care providers to serve as liaisons and provide information about novel interventions [35]. Genomics-specific factors including incomplete family history leading to unknown testing eligibility, clinician or patient concerns over the costs of testing and downstream care, racial bias in identifying the features of genetic disorders, lower expected utility because of poorer representation in genetic databases, and patient concerns over stigmatization, discrimination, or other misuses of information may all contribute to racial inequalities in genetic testing [36, 37].

The specific racial inequality in genetic testing we observed among potential early adopters indicates entrenched disparities and provides renewed motivation to improve equitable access to genomic medicine. Extensive research has investigated specific barriers to equitable access to genomic medicine, providing valuable insights into potential intervention targets. For instance, evidence of the influence of out-of-pocket costs and lack of access to family cascade testing indicates a need for comprehensive coverage for genetic testing, genetic counseling, and downstream care [38]. Improved racial bias training is needed for students and practicing clinicians [39]. Additionally, maintaining a commitment to include diverse populations in genetics research (including pragmatic implementation studies) is essential to building a knowledge base that supports equitable sharing of the benefits of genetic medicine – especially as the field moves toward greater reliance on retrospective clinical data that is poorly representative. Our study highlights an ongoing need to address disparities. Future studies should

Table 2. Logistic regression results for prior genetic testing

	Model 1		Model 2	
	odds ratio (95% CI)	*p* value	odds ratio (95% CI)	*p* value
Race: Black	0.43 (0.27, 0.68)	<0.001	0.57 (0.35, 0.94)	0.028
Age	1.00 (0.97, 1.03)	0.836	1.01 (0.97, 1.04)	0.756
Gender: male	0.74 (0.50, 1.11)	0.145	0.70 (0.46, 1.06)	0.091
Educational attainment (scale)	---	---	1.27 (0.98, 1.65)	0.073
Income >$100,000	---	---	1.66 (1.05, 2.62)	0.029
Big Five: extraversion	1.03 (0.80, 1.32)	0.817	1.01 (0.79, 1.30)	0.929
Big Five: agreeableness	0.93 (0.64, 1.37)	0.722	0.98 (0.67, 1.45)	0.934
Big Five: conscientiousness	1.05 (0.75, 1.48)	0.760	1.07 (0.76, 1.51)	0.690
Big Five: neuroticism	0.95 (0.69, 1.32)	0.774	0.92 (0.66, 1.28)	0.623
Big Five: openness	1.15 (0.82, 1.61)	0.416	1.02 (0.71, 1.46)	0.893
Information avoidance	0.88 (0.71, 1.09)	0.256	0.90 (0.72, 1.12)	0.350
Tolerance for uncertainty	0.97 (0.76, 1.24)	0.805	1.01 (0.78, 1.30)	0.938
Self-affirmations	1.17 (0.93, 1.46)	0.187	1.19 (0.94, 1.51)	0.155
Subjective numeracy	---	---	0.87 (0.70, 1.08)	0.200
Knowledge of genetics				
Sequencing limitations	---	---	1.03 (0.95, 1.12)	0.420
Sequencing benefits	---	---	0.98 (0.80, 1.06)	0.636
Heredity concepts	---	---	1.16 (1.05, 1.27)	0.003
Perceived value of genetics	0.81 (0.64, 1.03)	0.089	0.89 (0.69, 1.14)	0.352
Attitudes toward testing				
Preventable/treatable	1.05 (0.70, 1.58)	0.805	1.01 (0.67, 1.53)	0.951
Non-preventable/non-treatable	0.91 (0.76, 1.10)	0.352	0.94 (0.77, 1.14)	0.523
Reproductive utility	1.19 (0.88, 1.61)	0.249	1.19 (0.88, 1.62)	0.259
Intentions to learn genetic results				
Preventable/treatable	1.09 (0.86, 1.38)	0.471	1.06 (0.84, 1.34)	0.605
Non-preventable/non-treatable	1.08 (0.87, 1.34)	0.470	1.12 (0.89, 1.38)	0.365
Reproductive utility	0.90 (0.71, 1.15)	0.419	0.89 (0.70, 1.13)	0.339
Perceived global health	0.70 (0.55, 1.12)	0.190	0.70 (0.48, 1.03)	0.070
Has coronary artery disease	1.13 (0.66, 1.92)	0.655	1.20 (0.69, 2.01)	0.520
Perceived comparative risk	1.08 (0.94, 1.23)	0.289	1.05 (0.92, 1.22)	0.413
Constant	0.14 (0.00, 10.7)	0.378	0.07 (0.00, 6.30)	0.249
Pseudo R^2	0.0387		0.0683	
Log likelihood	−413.73		−400.99	
N	908		908	
bic	977.3		992.7	
aic	871.5		858.0	

examine the impact of expanding insurance coverage of genetic testing and downstream care, improving provider education and workforce development, and diversifying genomics databases. We can thus work toward rectifying the racial disparities in genomic medicine and fostering a more equitable healthcare landscape.

We used self-identified race as a proxy for sociological variables, including the structural and individual effects of racism. We recognize that there is a wide range of lived experience and ancestry within both racially defined cohorts, and we are wary of racial essentialism. Just as race as a proxy for genetic ancestry obfuscates genetic causes of phenotypic variation or disease mechanisms, race as a proxy for racism risks racial determinism, and obfuscates the specific effects of racism that vary across settings and individuals. As the 2023 National Academies Report on Population Descriptors in Genetics and Genomics Research states, "many elements of racial thinking, including essentialism and biological determinism, have influenced modern thinking around human genetics, to the marginalization of some peoples and the benefit of others" [40]. Racial and cultural essentialism, even when race is construed as a social construct, can be problematic. Compared to clinicians who see racial disparities as a product of differences under social conditions, clinicians who believe cultural differences (e.g.,

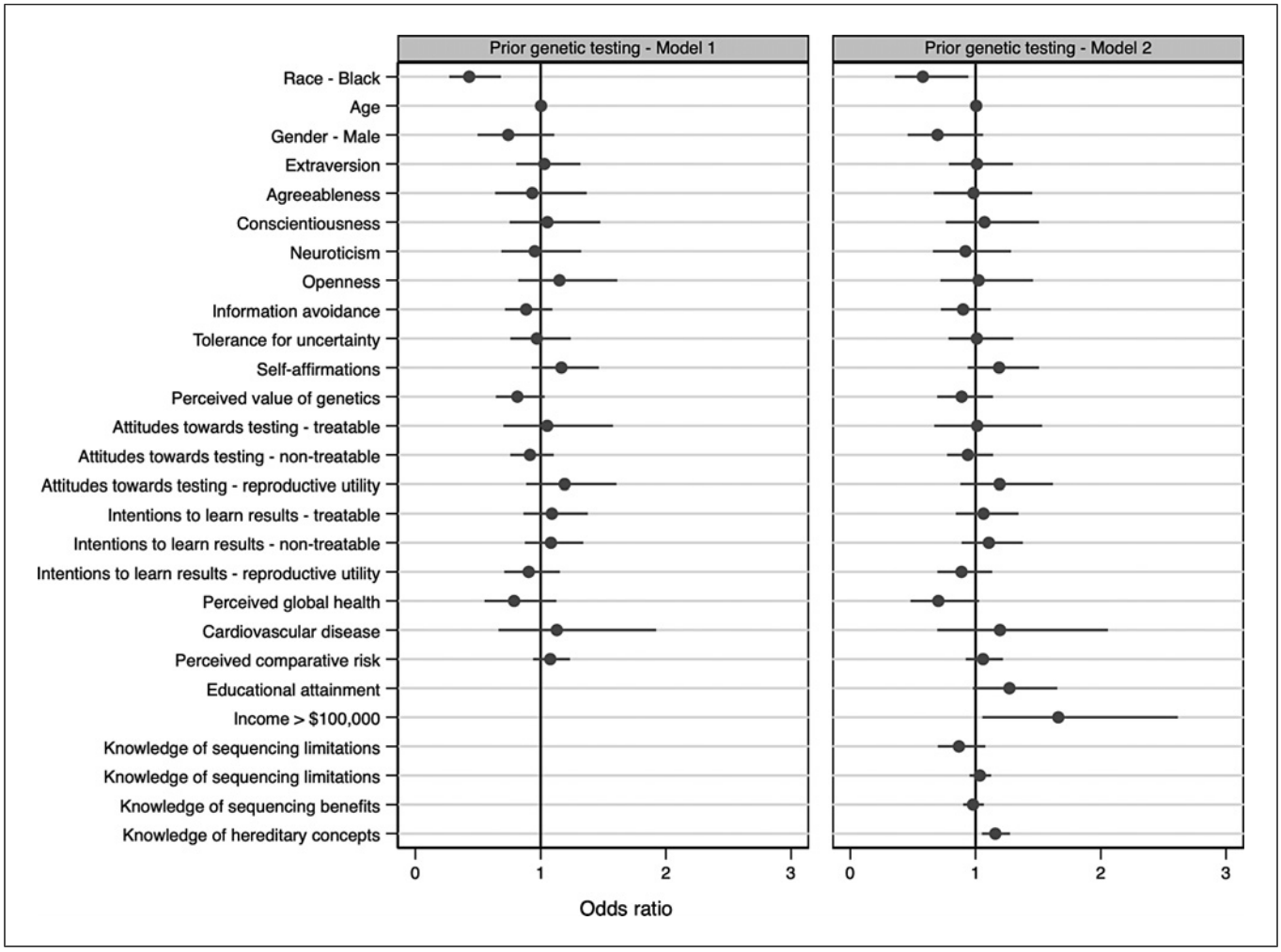

Fig. 1. Logistic regression results for associations with prior genetic testing. The figure displays odds ratios and 95% confidence intervals (error bars) from two logistic regression models examining the associations between individual-level characteristics and prior genetic testing among research participants. Model 1 does not control for income, education, and knowledge variables, while model 2 does. Odds ratios greater than 1 indicate positive associations, and odds ratios less than 1 indicate negative associations.

beliefs about health or the value of diet or exercise) drive racial disparities in health outcomes are more likely to use perceived race in their medical decision-making [41]. We join the call for researchers and entities tasked with collecting demographic data to adopt measures of social disadvantage, structural racism, and experienced racism [42, 43].

Limitations

The participants in this study may not be generalizable to the broader population. As noted, ClinSeq® participants had characteristics associated with better access to genetic testing compared to the general US public. For example, nearly 90% of white and 66% of Black participants had a college degree, compared to 34% of white and 22% of Black people over age 25 in the US [44]. Similarly, 78% of white and 38% of Black ClinSeq® participants had annual household incomes over $100,000, compared to 37% of white and 20% of Black householders in the US [45]. Recruitment in and around Bethesda, MD in the DC suburbs, in close geographical proximity to the NIH campus where this study was conducted, could contribute to the atypical characteristics of these participants. Even greater barriers to accessing clinical genetic testing likely exist for non-research participants and the US population outside of this region.

Table 3. Linear regression results for non-genetic clinical screening

	Model 3		Model 4	
	β (95% CI)	*p* value	β (95% CI)	*p* value
Race: Black	−0.06 (−0.16, 0.05)	0.286	−0.05 (−0.16, 0.06)	0.391
Age	0.03 (0.03, 0.04)	<0.001	0.03 (0.02, 0.04)	<0.001
Gender: male	−0.38 (−0.47, −0.29)	<0.001	−0.42 (−0.51, −0.32)	<0.001
Educational attainment	---	---	0.04 (−0.02, 0.09)	0.182
Income >$100,000	---	---	0.09 (−0.01, 0.19)	0.068
Big Five: extraversion	0.06 (−0.00, 0.12)	0.057	0.05 (−0.01, 0.11)	0.113
Big Five: agreeableness	−0.01 (−0.10, 0.08)	0.818	−0.02 (−0.11, 0.07)	0.651
Big Five: conscientiousness	0.08 (−0.00, 0.16)	0.052	0.07 (−0.01, 0.15)	0.068
Big Five: neuroticism	0.05 (−0.03, 0.13)	0.221	0.04 (−0.04, 0.12)	0.306
Big Five: openness	−0.04 (−0.12, 0.04)	0.327	−0.04 (−0.12, 0.04)	0.294
Information avoidance	0.01 (−0.03, 0.05)	0.550	0.03 (−0.02, 0.08)	0.267
Tolerance for uncertainty	−0.01 (−0.07, 0.05)	0.758	−0.01 (−0.07, 0.04)	0.614
Self-affirmations	−0.01 (−0.06, 0.05)	0.805	−0.02 (−0.07, 0.03)	0.490
Subjective numeracy	---	---	0.02 (−0.02, 0.07)	0.324
Knowledge of genetics				
Sequencing limitations	---	---	−0.01 (−0.03, 0.01)	0.407
Sequencing benefits	---	---	−0.01 (−0.03, 0.01)	0.192
Heredity concepts	---	---	−0.01 (−0.04, 0.01)	0.282
Perceived value of genetics	---	---	0.07 (0.02, 0.13)	0.013
Attitudes toward testing				
Preventable/treatable	---	---	−0.05 (−0.13, 0.04)	0.308
Non-preventable	---	---	0.02 (−0.03, 0.06)	0.476
Reproductive utility	---	---	−0.02 (−0.08, 0.05)	0.605
Intentions to learn results				
Preventable/treatable	---	---	0.00 (−0.05, 0.06)	0.863
Non-preventable	---	---	0.02 (−0.03, 0.06)	0.536
Reproductive utility	---	---	0.02 (−0.04, 0.08)	0.486
Perceived global health	−0.03 (−0.11, 0.06)	0.561	−0.03 (−0.12, 0.06)	0.544
Cardiovascular disease	0.36 (0.23, 0.49)	<0.001	0.32 (0.19, 0.46)	<0.001
Perceived comparative risk	---	---	0.05 (0.02, 0.08)	0.002
Constant	0.48 (−0.35, 1.32)	0.254	0.13 (−0.88, 1.13)	0.807
Adjusted R^2	0.159		0.181	
Log likelihood	−870.54		−850.86	
N	918		918	
bic	1,836.6		1,892.7	
aic	1,769.1		1,757.7	

However, we were specifically interested here in research participants as potential early adopters and how their unusual characteristics may position them in the technology diffusion process. By nature of their enrollment, we can assume that participants in our study were unusually motivated and interested in genetic testing. We expect that they have a greater interest in and utilization of non-research genetic testing compared to the general population. Nevertheless, the racial inequality we observed in prior genetic testing is nearly identical to a recent nationally representative sample, which found that Black respondents were half as likely to have prior genetic testing when controlling for other demographic factors [46].

Because the prior testing was self-reported, there may be underreporting of prior testing if participants were not aware that clinical tests included genetic testing or did not remember it as genetic testing. For example, patients might not know if prenatal screening was genetic or non-genetic, or whether a tumor biopsy included genetic testing.

The first round of ClinSeq enrollment (all of the non-Hispanic white participants in the study) was completed in 2007–2013, and the second round of recruitment of Black and African American participants was completed in 2012–2017. Access to, awareness of, and acceptance of genetic testing likely increased during that time, meaning that participants enrolled at later stages should have been more

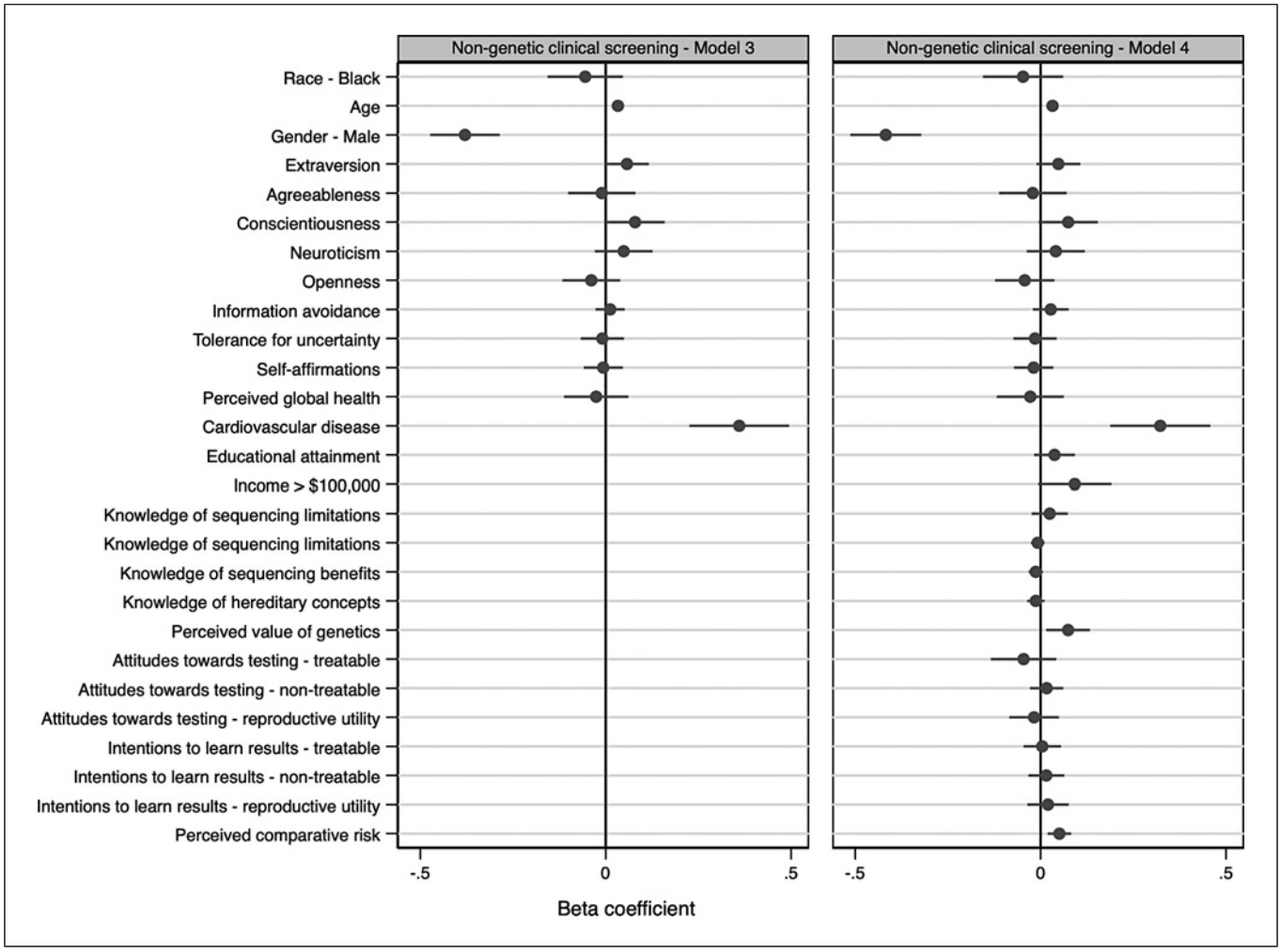

Fig. 2. Linear regression results for associations with non-genetic clinical screening. The figure displays regression coefficients and 95% confidence intervals (error bars) from two linear regression models examining the associations between individual-level characteristics and non-genetic clinical screening among research participants. Model 3 does not control for income, education, knowledge, and genetics-specific variables, while model 4 does. Coefficients greater than 0 indicate positive associations, and coefficients less than 0 indicate negative associations.

likely to have prior genetic testing. However, we saw the opposite – the Black and African American participants enrolled in the later round were less likely to have prior testing. If the participants had all been enrolled at the same time, we would expect to see an even larger difference. Whether research participants enrolled as recently as 2017 are early adopters of genomic technology could be questioned. But genomic medicine is not yet become routine in most clinical contexts, and we still consider participants in genome sequencing to be at the forefront of innovation.

An additional important difference between the two cohorts was the targeted enrollment of patients with coronary artery disease in the first, mostly white cohort only. Patients with diagnosed diseases may have more regular contact with the healthcare system, giving them more opportunities to get genetic testing or other healthcare screening. On the other hand, they could be more burdened with managing their coronary artery disease and avoid unrelated preventive screening. Either way, we considered it critical to control for coronary artery disease status in our regressions and it proved to be an important factor in non-genetic screening – people with coronary artery disease were more likely to report greater use of non-genetic screening.

We were not able to differentiate the purposes of prior genetic testing in our sample, which limits what we can say about potential early adopters of genetic medicine or non-medical genetic testing. Participants were asked whether they had any prior genetic testing, and the

context or purpose was not specified. Testing could have been ordered in any context (direct-to-consumer, ordered by a primary care clinician, or ordered by a genetics specialist), and for any purpose (e.g., ancestry, parentage, pharmacogenomics, risk prediction, reproductive planning, or disease diagnosis). Others found that Black, Hispanic, and non-Hispanic white respondents were equally likely to report direct-to-consumer testing for ancestry, but Black and Hispanic patients were less likely to report clinical testing or direct-to-consumer testing for health reasons [47]. In our study, we would expect to see even greater racial disparities if the reason for prior testing had been restricted to clinical testing only. Therefore, our findings may be conservative.

Conclusions

Research participants exhibit the intrinsic characteristics of early adopters, making them key players in the diffusion of medical innovations. We report that self-identified Black and non-Hispanic white participants are very similar along intrinsic personality factors but differ along sociodemographic and resource factors. These potential leaders in innovation are inhibited by access and resource constraints. Relying on the natural diffusion of genomic medicine runs the risk of leaving many people out. Research studies enrolling populations who are diverse along cultural, sociodemographic, educational, and other characteristics can thus provide a window into potential early adopters whose access to new technology may be otherwise limited.

Disclaimer

The work discussed here does not necessarily represent the opinion or policy of the National Institutes of Health or the Department of Health and Human Services.

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Statement of Ethics

The present analysis used de-identified, individual-level data. This study protocol was reviewed by the University of North Carolina Office of Human Research Ethics Institutional Review Board, study number 18-3283, and determined to not constitute human subjects research. All data generation procedures, including recruitment, the consent process, data collection, and data management were conducted following federal regulations and under the oversight of the National Human Genome Research Institute intramural IRB. Written informed consent was obtained from all individuals.

Conflict of Interest Statement

M.C.R.'s spouse holds stock in Merck. L.G.B. is a member of the Illumina Medical Ethics Committee, receives research support from Merck, Inc., and receives honoraria from Cold Spring Harbor Laboratory Press and Wolters-Kluwer.

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Author Contributions

Conceptualization: K.W.S., M.C.R., E.T., and W.M.P.K.; investigation: K.L.L. and L.G.B.; data curation: K.L.L.; formal analysis and writing – original draft: K.W.S.; writing – review and editing: W.M.P.K., L.C., K.L.L., L.G.B., E.T., and M.C.R.; and supervision: M.C.R. and E.T.

Data Availability Statement

Please contact the corresponding author to discuss data availability. The ClinSeq consent dictates that any secondary use of data must be reviewed and approved by the original study team. Statistical analysis code for this paper will be provided by email upon request.

References

1 Phillips KA, Deverka PA, Hooker GW, Douglas MP. Genetic test availability and spending: where are we now? Where are we going? Health Aff. 2018;37(5):710–6.
2 Fraiman YS, Wojcik MH. The influence of social determinants of health on the genetic diagnostic odyssey: who remains undiagnosed, why, and to what effect? Pediatr Res. 2021 Jan;89(2):295–300.
3 Muller C, Lee SM, Barge W, Siddique SM, Berera S, Wideroff G, et al. Low referral rate for genetic testing in racially and ethnically diverse patients despite universal colorectal cancer screening. Clin Gastroenterol Hepatol. 2018 Dec;16(12):1911–8.e2.
4 Yarrington CD, Smith-Lin C, Neuhalfen R, Hanchate A, Connors P, Wang C. Racial and ethnic differences in uptake of cell-free fetal DNA aneuploidy screening in an urban safety net hospital. Prenat Diagn. 2021;41(11):1389–94.

5 Brothers KB, Rothstein MA. Ethical, legal and social implications of incorporating personalized medicine into healthcare. Per Med. 2015 Jan;12(1):43–51.
6 Khoury MJ, Bowen S, Dotson WD, Drzymalla E, Green RF, Goldstein R, et al. Health equity in the implementation of genomics and precision medicine: a public health imperative. Genet Med. 2022 Apr;24(8):1630–9.
7 Dearing JW, Cox JG. Diffusion of innovations theory, principles, and practice. Health Aff. 2018 Feb;37(2):183–90.
8 Rogers E. Diffusion of innovations. 2nd ed. New York: Free Press; 2003.
9 Cain M, Mittman R, Institute for the Future ; California HealthCare Foundation. Diffusion of innovation in health care. Oakland, Calif.: California Healthcare Foundation; 2002.
10 Dedehayir O, Ortt RJ, Riverola C, Miralles F. Innovators and early adopters in the diffusion of innovations: a literature review. Int J Innov Mgt. 2017 Dec;21(8):1740010.
11 Zachrison KS, Yan Z, Samuels-Kalow ME, Licurse A, Zuccotti G, Schwamm LH. Association of physician characteristics with early adoption of virtual health care. JAMA Netw Open. 2021 Dec;4(12):e2141625.
12 Kennedy B, Funk C. 28% of Americans are "strong" early adopters of technology (Internet). Pew Research Center; 2016. (cited 2022 Jan 10). Available from: https://www.pewresearch.org/fact-tank/2016/07/12/28-of-americans-are-strong-early-adopters-of-technology/.
13 Groeneveld PW, Sonnad SS, Lee AK, Asch DA, Shea JE. Racial differences in attitudes toward innovative medical technology. J Gen Intern Med. 2006 Jun;21(6):559–63.
14 Lewis KL, Heidlebaugh AR, Epps S, Han PKJ, Fishler KP, Klein WMP, et al. Knowledge, motivations, expectations, and traits of an African, African-American, and Afro-Caribbean sequencing cohort and comparisons to the original ClinSeq® cohort. Genet Med. 2019 Jun;21(6):1355–62.
15 Zoltick ES, Linderman MD, McGinniss MA, Ramos E, Ball MP, Church GM, et al. Predispositional genome sequencing in healthy adults: design, participant characteristics, and early outcomes of the PeopleSeq Consortium. Genome Med. 2019 Feb;11(1):10.
16 Lewis KL, Han PKJ, Hooker GW, Klein WMP, Biesecker LG, Biesecker BB. Characterizing participants in the ClinSeq genome sequencing cohort as early adopters of a new health technology. PLoS One. 2015 Jul;10(7):e0132690.
17 Krok-Schoen JL, Baker TA. Race differences in personality and affect between older white and Black patients: an exploratory study. J Racial Ethnic Health Disparities. 2014 Dec;1(4):283–90.
18 Foldes HJ, Duehr EE, Ones DS. Group differences in personality: meta-analyses comparing five U.S. Racial groups. Person Psychol. 2008;61(3):579–616.
19 Meyer MN, Appelbaum PS, Benjamin DJ, Callier SL, Comfort N, Conley D, et al. Wrestling with social and behavioral genomics: risks, potential benefits, and ethical responsibility. Hastings Cent Rep. 2023;53(Suppl 1):S2–49.
20 Rosenberg NA. A population-genetic perspective on the similarities and differences among worldwide human populations. Hum Biol. 2011 Dec;83(6):659–84.
21 Timmermans S, Kaufman R. Technologies and health inequities. Annu Rev Sociol. 2020;46(1):583–602.
22 Biesecker LG, Mullikin JC, Facio FM, Turner C, Cherukuri PF, Blakesley RW, et al. The ClinSeq project: piloting large-scale genome sequencing for research in genomic medicine. Genome Res. 2009 Sep;19(9):1665–74.
23 Andersen RM, Davidson PL, Baumeister SE. Improving access to care. In: Kominski GF, editor. Changing the U.S. health care system: key issues in health services policy and management, 4th Edition | Wiley. 4th ed. Jossey-Bass; 2013. p. 37.
24 Taber JM, Klein WMP, Ferrer RA, Lewis KL, Harris PR, Shepperd JA, et al. Information avoidance tendencies, threat management resources, and interest in genetic sequencing feedback. Ann Behav Med. 2015 Aug;49(4):616–21.
25 Fagerlin A, Zikmund-Fisher BJ, Ubel PA, Jankovic A, Derry HA, Smith DM. Measuring numeracy without a math test: development of the subjective numeracy scale. Med Decis Making. 2007 Sep;27(5):672–80.
26 Kaphingst KA, Facio FM, Cheng M-R, Brooks S, Eidem H, Linn A, et al. Effects of informed consent for individual genome sequencing on relevant knowledge. Clin Genet. 2012 Nov;82(5):408–15.
27 Turbitt E, Roberts MC, Ferrer RA, Taber JM, Lewis KL, Biesecker LG, et al. Intentions to share exome sequencing results with family members: exploring spousal beliefs and attitudes. Eur J Hum Genet. 2018 May;26(5):735–9.
28 Facio FM, Eidem H, Fisher T, Brooks S, Linn A, Kaphingst KA, et al. Intentions to receive individual results from whole-genome sequencing among participants in the ClinSeq study. Eur J Hum Genet. 2013 Mar;21(3):261–5.
29 Hooker GW, Umstead KL, Lewis KL, Koehly LK, Biesecker LG, Biesecker BB. Engagement and communication among participants in the ClinSeq genomic sequencing study. Genet Med. 2017 Jan;19(1):98–103.
30 Taber JM, Klein WMP, Ferrer RA, Lewis KL, Biesecker LG, Biesecker BB. Dispositional optimism and perceived risk interact to predict intentions to learn genome sequencing results. Health Psychol. 2015 Jul;34(7):718–28.
31 McGuire TG, Alegria M, Cook BL, Wells KB, Zaslavsky AM. Implementing the Institute of medicine definition of disparities: an application to mental health care. Health Serv Res. 2006 Oct;41(5):1979–2005.
32 Peterson EB, Taber JM, Klein WMP. Information avoidance, self-affirmation, and intentions to receive genomic sequencing results among members of an african descent cohort. Ann Behav Med. 2021 Jun;56(2):205–11.
33 Turbitt E, Roberts MC, Hollister BM, Lewis KL, Biesecker LG, Klein WMP. Ethnic identity and engagement with genome sequencing research. Genet Med. 2019 Aug;21(8):1735–43.
34 Weiss D, Rydland HT, Øversveen E, Jensen MR, Solhaug S, Krokstad S. Innovative technologies and social inequalities in health: a scoping review of the literature. PLoS One. 2018 Apr;13(4):e0195447.
35 Beal AC, Doty MM, Hernandez SE, Shea KK, Davis K. Closing the divide: how medical homes promote equity in health care. The Commonwealth Fund; 2007.
36 Hull LE, Natarajan P. Self-rated family health history knowledge among All of Us program participants. Genet Med. 2022 Apr;24(4):955–61.
37 Popejoy AB, Ritter DI, Crooks K, Currey E, Fullerton SM, Hindorff LA, et al. The clinical imperative for inclusivity: race, ethnicity, and ancestry (REA) in genomics. Hum Mutat. 2018;39(11):1713–20.
38 Lin GA, Trosman JR, Douglas MP, Weldon CB, Scheuner MT, Kurian A, et al. Influence of payer coverage and out-of-pocket costs on ordering of NGS panel tests for hereditary cancer in diverse settings. J Genet Couns. 2022 Feb;31(1):130–9.
39 Pollock B, Wetherill L, Delk P, Wesson M, Rucker S, Goodman Z, et al. Diversity training experiences and factors associated with implicit racial bias among recent genetic counselor graduates of accredited programs in the United States and Canada. J Genet Couns. 2022;31(3):792–802.
40 Committee on the use of race, ethnicity, and ancestry as population Descriptors in genomics research, board on health sciences policy, committee on population, health and medicine division, division of behavioral and social sciences and education, national Academies of sciences, engineering, and medicine. Using population descriptors in genetics and genomics research: a new framework for an evolving field. Washington (D.C.): National Academies Press; 2023.
41 Okah E, Cronholm PF, Crow B, Persaud A, Westby A, Bonham VL. Race-based care and beliefs regarding the etiology of racial differences in health outcomes. Am J Prev Med. 2023 Apr;64(4):477–82.
42 Ioannidis JPA, Powe NR, Yancy C. Recalibrating the use of race in medical research. JAMA. 2021 Feb;325(7):623–4.

43 Hardeman RR, Homan PA, Chantarat T, Davis BA, Brown TH. Improving the measurement of structural racism to achieve antiracist health policy. Health Aff. 2022 Feb;41(2):179–86.
44 McElrath K, Martin M. Bachelor's degree attainment in the United States: 2005–2019. American Community Survey Briefs; 2021.
45 Shrider EA, Kollar M, Chen F, Semega J. Income and poverty in the United States: 2020: current population reports. 2021.
46 Tiner JC, Mechanic LE, Gallicchio L, Gillanders EM, Helzlsouer KJ. Awareness and use of genetic testing: an analysis of the health information national trends survey 2020. Genet Med. 2022 Dec;24(12):2526–34.
47 Carroll NM, Blum-Barnett E, Madrid SD, Jonas C, Janes K, Alvarado M, et al. Demographic differences in the utilization of clinical and direct-to-consumer genetic testing. J Genet Couns. 2020;29(4):634–43.