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Precision medicine: Familiarity, perceived health drivers, and genetic testing considerations across health literacy levels in a diverse sample

Jessica R. Williams^{1,2}, Vivian M. Yeh^{3,4}, Marino A. Bruce^{5,6}, Carolyn Szetela⁸, Flora Ukoli⁹, Consuelo H. Wilkins^{4,7}, and Sunil Kripalani^{3,4}

¹University of North Carolina at Chapel Hill, School of Nursing, Chapel Hill, NC

²University of Miami, School of Nursing and Health Studies, Coral Gables, FL

³Center for Clinical Quality and Implementation Research, Vanderbilt University Medical Center, Nashville, TN

⁴Division of General Internal Medicine and Public Health, Department of Medicine, Vanderbilt University Medical Center, Nashville, TN

⁵Center for Medicine, Health, and Society, Vanderbilt University, Nashville, TN

⁶Center for Research on Men's Health, Vanderbilt University, Nashville, TN

⁷Meharry-Vanderbilt Alliance, Nashville, TN

⁸Department of Professional and Medical Education, Meharry Medical College, Nashville, TN

⁹Department of Surgery, Meharry Medical College, Nashville, TN

Abstract

A clear awareness of a patient's knowledge, values, and perspectives is an important component of effective genetic counseling. Advances in precision medicine, however, have outpaced our understanding of patient perceptions of this new approach. Patient views may differ across the

Animal Studies

Corresponding Author Jessica R. Williams, PhD, MPH, PHNA-BC, University of North Carolina at Chapel Hill, School of Nursing, 5004 Carrington Hall, Campus Box 7460, Chapel Hill, NC 27599-7460, 919-966-3629, jrober65@email.unc.edu. Authorship Contributions

Jessica R. Williams contributed to the research design, data analysis, interpretation of data, and writing the first draft of the manuscript. Vivian M. Yeh was responsible for data acquisition, analysis, and interpretation and contributed to the writing of the manuscript. Marino A. Bruce contributed to the research design, interpretation of data, and critical review and revision of the manuscript. Carolyn Szetela contributed to the research design, interpretation of data, and critical review and revision of the manuscript. Flora Ukoli contributed to data acquisition and critical review and revision of the manuscript. Flora Ukoli contributed to data acquisition and critical review and revision of the manuscript. Sunil Kripalani contributed to the research design, data interpretation, and critical review and revision of the manuscript. Sunil Kripalani contributed to the research design, data analysis, interpretation of data, and critical review and revision of the manuscript. All authors read and approved the final manuscript and agree to be accountable for all aspects of the work.

Conflict of Interest

Authors Jessica R. Williams, Vivian M. Yeh, Marino A. Bruce, Carolyn Szetela, Flora Ukoli, Consuelo H. Wilkins, and Sunil Kripalani declare that they have no conflict of interest.

Human Studies and Informed Consent

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all participants for being included in the study.

No animal studies were carried out by the authors for this article.

three domains of precision medicine (genetics, behavioral, and environmental determinants of health), ethnic/racial groups, and health literacy levels. This study describes and compares group differences in familiarity, perceptions, and preferences for precision medicine in a diverse sample. Between 2016 and 2017, 252 participants completed a 10–15 minute survey in three primary care clinics in Florida and Tennessee. The final sample was 42.5% African American/Black, 25.8% Hispanic/Latino, 25.0% White and 6.7% other ethnicity/race. Less than a quarter of participants reported being familiar with the term "precision medicine," but were more familiar with basic genetic terms. Participants with higher health literacy reported greater familiarity with terms (p . 003). African Americans/Black participants were more likely to identify ethnicity/race and discrimination as influencing their health (p .004). When deciding to get a genetic test, individuals across ethnic/racial groups shared similar considerations. Those with higher health literacy, however, gave significantly greater importance to provider trust (p .008). Given the recent emergence of precision medicine, at present there may be limited differences in patient perceptions across ethnic/racial groups. Culturally sensitive efforts, tailored to health literacy level, may aid equitable precision medicine uptake.

Keywords

precision health; health disparities; health literacy; attitude to health; race/ethnicity

Background

Precision medicine is a rapidly expanding field that is shifting from bench to bedside with the advent of advanced clinical applications such as precision oncology and pharmacogenetics (Collins & Varmus, 2015; Phillips & Van Bebber, 2004; Phillips et al., 2001; Roberts et al., 2017; Schleidgen et al., 2013). This approach to prevention, screening, and treatment considers each individual's unique expression of genetic, behavioral, and environmental factors to provide "the right treatment to the right person at the right time" (Ginsburg & Willard, 2009; Mirnezami et al., 2012). As such, the promise of precision medicine has compelling implications for benefiting population heath but can present new challenges for the field of genetic counseling (Ashley, 2015; Collins & Varmus, 2015; Khoury et al., 2012).

One challenge is that it cannot be assumed that precision medicine will be "actionable" in real world settings or that all patients stand to benefit equally (Bayer & Galea, 2015). The cultural and structural context of underserved racial/ethnic groups and economically-challenged populations can impact how members of these groups think about and act on their health (Egede, 2006; Williams et al., 2008; Williams et al., 1997); therefore, it is important to understand how diverse patients may regard aspects of precision medicine in order to optimize implementation (Bentley et al., 2017). Additionally, individuals with lower health literacy may have less familiarity to concepts in precision medicine, be unaware of gaps in their existing knowledge, and how to best apply new information to workable solutions (Paasche-Orlow & Wolf, 2007; Sorensen et al., 2012). Exploring how individuals in various ethnic and racial groups and with different health literacy levels view precision

medicine is critical for genetic counselors to promoting equitable uptake and implementation while avoiding deepening health disparities (Dankwa-Mullan et al., 2015).

Before existing precision medicine approaches can be successfully implemented for all segments of the United States (U.S.) population, these challenges need to be addressed across multiple stakeholders (e.g., patients, providers, health care systems, insurers, policy, etc.) (Mirnezami et al., 2012). While independent lines of research have demonstrated that both behavior (Glanz et al., 2008; Idler & Angel, 1990) and environment (Gordon-Larsen et al., 2006; Jackson, 2003) have a robust influence on health, the majority of the precision medicine field has focused on genetics to the exclusion of how behavior and environment may complement or impede precision medicine efforts (Ginsburg & Willard, 2009; Schleidgen et al., 2013). Given the critical role genetic counselors are likely to play in the advancement of precision medicine, additional efforts are needed to help these professionals understand patient perceptions about genetics, environment, behaviors and perhaps their interaction in order to best realize the promise of precision medicine in clinical practice (Davis & Shanley, 2017; Khoury, 2017; Riley et al., 2015). The purpose of this paper is to report results from an analysis of survey data drawn from a diverse population in an effort to gain a better understanding of patient-level factors (ethnic/racial group, health literacy level) that may impede uptake and whether these patient-level factors influence perceptions across three precision medicine domains (genetics, behavior, and environment).

Methods

Design and Procedures.

This is a cross-sectional survey study of primary care patients who received care at institutions participating in the Precision Medicine and Health Disparities Collaborative. The Precision Medicine and Health Disparities Collaborative is a National Institutes of Health Center of Excellence in Precision Medicine and Population Health, led by Vanderbilt University Medical Center, Meharry Medical College, and the University of Miami. The mission of the Collaborative is to provide a diverse group of researchers with the infrastructure and resources to develop collaborative research teams that use precision medicine approaches to eliminate disparities in health outcomes, specifically among African Americans and Latinos.

The study was conducted in primary care clinics at 1) Meharry Medical College, Nashville, TN; 2) The University of Miami Hospital, Miami, FL; and 3) Vanderbilt University Medical Center, Nashville, TN. These study sites were selected to ensure representation from African Americans, Hispanics/Latinos, and Whites. The study employed a unified protocol and Institutional Review Boards at each academic institution approved the study.

Study enrollment occurred between November 2016 and March 2017. Participants were recruited in primary care waiting rooms. All participants provided informed consent, completed the 10–15 minute survey on a tablet computer via a secure web-based survey tool (Harris et al., 2009) and were compensated \$5. Research assistants remained with the participant during data collection to answer any questions they had regarding survey items. Informed consent and surveys were conducted in English at all sites except the University of

Miami Hospital, where participants were given the option to complete in either English or Spanish by bilingual research assistants.

Participants.

Adults age 18 years and older were considered eligible if they were primary care patients at the respective sites and could complete a survey on a tablet in English (all three sites) or Spanish (University of Miami Hospital).

Instrumentation.

Participants were asked to self-report race, Hispanic/Latino ethnicity, age, sex/gender, place of birth, and education level. Since different individuals may prefer different terms when describing their ethnicity and race, individuals were asked to endorse if they were "Hispanic/Latino" and "African American/Black." Health literacy was assessed with the validated 3-item Brief Health Literacy Screen (Chew et al., 2004; Chew et al., 2008), measured on a five-point Likert type scale, with total literacy scores ranging from 3 to 15. A score of 10 or above indicates adequate health literacy (McNaughton et al., 2014).

Familiarity, perceptions, and values related to precision medicine were assessed using three sets of questions (see Online Resource 1 for the measures in full). Currently, no widelyaccepted tools exist to measure these concepts; as such, instruments were developed based on our previous research conducted by the study team (Wilkins, 2016) and extant literature in the areas of precision medicine, genetics, and health disparities. Our instrument to assess familiarity of terms specific to precision medicine included terms from genetics (Erby et al., 2008), personalized medicine (KRC Research, 2014), and the precision medicine literature. Thirteen terms were assessed and response options ranged from 1 "not at all" familiar to 5 "extremely" familiar. Patient perceptions of how much different factors affect personal health were measured via 12 items. Items were selected to capture domains characteristic of precision medicine and health disparities (i.e., cultural background, genetics, health literacy, social-economic status, and environment). Response options ranged from 1 indicating "not at all" to 5 a "very large amount." A total of six items assessed values considered important when deciding to get a genetic test. These included factors shown in prior research (Martinez et al., 2017; Saulsberry & Terry, 2013; Walker et al., 2014) to be important considerations for participating in genetic testing (i.e., trust, privacy, cost, counseling) and genetic research (i.e., receiving test results, receiving payment for blood or tissue donation). Individual responses ranged from 1 "not important" to 5 "extremely important."

Study documents were translated using a standardized protocol following a translation-back translation method, in which a qualified translator first translates the English document into Spanish, then a second qualified translator translates the Spanish version back to English, and finally a third individual compares the two English documents for consistency. All translated documents were reviewed by five members of the target population for clarity.

Data Analysis.

Descriptive statistics were used to calculate demographic characteristics. To create ethnic/ racial groups of sufficient size for statistical comparison, participants were classified as

Hispanic/Latino, non-Hispanic African American/Black, or non-Hispanic White based on their self-report (Singer et al., 2004). Participants who did not fit into the three ethnic/racial categories (e.g., those who endorsed themselves as American Indian or Alaska Natives, Asians, Native Hawaiian or Other Pacific Islander and those who preferred not to answer) were excluded from analyses of ethnic/racial group differences due to their limited numbers (n=17).

The health literacy levels of the three ethnic/racial groups were compared using ANOVA with follow-up post-hoc Tukey tests. A series of multivariable regression models were conducted to examine responses to precision medicine survey items (i.e., familiarity, perceptions, and values related to precision medicine) by ethnic/racial group and by health literacy level. Outcome variables (i.e., precision medicine survey items) were treated as continuous in the regression models. Due to the association of ethnicity/race with health literacy, ethnic/racial group membership (reference category White) and a continuous measure of health literacy were simultaneously entered into models as predictors to examine their independent association with precision medicine survey items. Additionally, education level, place of birth, and survey language were added as covariates to control for potential confounding with the main predictor variables. Collinearity diagnostics were conducted to prevent overfitting of the covariates in the model. No issues with multi-collinearity were found between variables. Bonferroni corrections were used to manage the Type I error associated with multiple hypothesis testing (Bland & Altman, 1995). There were three question sets and each contained a different number of items. The number of items was considered the number of hypothesis tests in each of the three p-value corrections. To maximize interpretability, result tables present outcome variables and health literacy as dichotomous variables. Results for statistical significance reported in tables correspond to the regression models which treat outcome variables and health literacy as continuous. All data analyses were conducted using SPSS 21 (IBM, Armonk, NY). The datasets generated and analyzed during the current study are available from the corresponding author on reasonable request.

Results

Demographics.

A total of 252 out of 518 (48.6%) patients approached completed the survey. The response rates varied at each site (Vanderbilt University Medical Center: 43.5%; The University of Miami Hospital: 50.0%; Meharry Medical College: 61.0%). The most common reason patients declined was that they did not have enough time to complete the survey before their appointment. Appointment wait times can vary within and across clinics and this factor is likely to impact differences in response rates across sites as well.

Participant demographics are presented in Table I. The mean age was 51.47 years and 65.1% of the sample was female. Overall, 42.5% self-identified as African American/Black, 25.8% as Hispanic/Latino, 25.0% as White, and 6.7% did not report membership in the three aforementioned groups. A total of 49.2% had a college degree or higher. The median health literacy score was 13 with an interquartile range of 11 to 15 and 86.1% demonstrated adequate health literacy (score 10). Lastly, 66.7% were born inside of the United States.

There were significant differences in the health literacy levels of the three ethnic/racial groups ($F_{2,232}$ =9.07, p < .001). Participants who were White (M=13.22, SD=2.08) had significantly higher health literacy than those who were Hispanic/Latino (M=11.45, SD=2.72, p < .001), based on post-hoc Tukey-tests.

Familiarity with precision medicine terms (Table II).

Overall, less than a quarter (23.8%) of individuals reported themselves to be either "moderately" or "extremely" familiar with the term "precision medicine" as compared with "not at all," "slightly," and "somewhat" familiar. Familiarity with genetic terms was mixed, with the majority reporting familiarity with older terms like "gene" (63.9%) and "DNA" (71.0%) compared to more recent concepts like "pharmacogenomics" (19.0%) and "biobank" (17.9%). Less than a third (29.0%) reported themselves as familiar with the concept of "social determinants of health."

There were no ethnic/racial group differences in term familiarity. Compared to patients with inadequate health literacy, patients with higher health literacy reported significantly greater familiarity with 7 of the 13 terms related to genetics, lifestyle, and environment (all p-values .003). However, even among patients with adequate health literacy, less than 40% reported familiarity with modern terms like "precision medicine," "personalized medicine," "genomics," "biobank," "biomarkers," "pharmacogenomics," and "social determinants of health".

Perceptions of how much precision medicine factors affect personal health (Table III).

Among cultural, genetic, literacy, socioeconomic, and environmental factors which comprise precision medicine, no one area was perceived to have a dominant role in influencing personal health. For each area, 13.5% to 36.5% of the sample endorsed it as having either a "very large" or "large" amount of influence. Ethnic/racial group differences were found only in the questions related to culture. Those who were African American/Black were more likely than White participants to endorse that their "race or ethnicity" (p .004) and "discrimination" (p .004) influenced their health. Health literacy level did not impact how likely individuals rated the influence of these different aspects of precision medicine on their health.

Values considered important when deciding to get a genetic test (Table IV).

The majority of participants reported that trust in their providers, cost of the test, receiving the results of a genetic test, receiving counseling about test results and privacy were either "extremely" or "very" important when deciding to get a genetic test (63.9% to 83.7%). Those with higher health literacy placed greater importance on trust in their providers (p . 008). Overall, only a quarter (24.6%) reported that receiving payment for a tissue or blood donation was important; this belief was more common among African American/Black individuals as compared to White individuals (p .008).

Discussion

This study highlights important findings related to patients' understanding and perceptions of precision medicine, which can help guide genetic counselors in advancing precision medicine efforts. There were more similarities than differences in perceptions and understanding of precision medicine across groups in the sample. The majority of these differences were attributable to varying health literacy levels rather than ethnic/racial group membership. As the field of precision medicine continues its rapid growth, it is critical for those involved in its advancement, such as genetic counselors, to consider patients' understanding of, perceptions, and values related to precision medicine to ensure future success of these initiatives.

An important indicator of patient understanding of health information is familiarity with common terms. In this study, there was a general lack of familiarity with terms frequently associated with precision medicine. Participants tended to be more familiar with basic genetic terms (e.g., gene, DNA, hereditary) and less familiar with newer, more specialized precision medicine terms (e.g., biomarkers, pharmacogenomics, social determinants of health). Our findings also demonstrated that differences in term familiarity were attributable, in part, to health literacy levels and not ethnic/racial group membership. These findings suggest a need for broader public education and patient counseling regarding the specialized areas of precision medicine, building upon the familiarity many have with basic genetic terms and highlighting the importance of tailoring precision medicine materials and interventions based on literacy level.

Another possible explanation for differences in familiarity may be due to the "patientfriendliness" of each term. For example, 37.3% of participants were familiar with the term personalized medicine compared to 23.8% who reported being familiar with the term precision medicine. It may be that patients are more likely to believe they understand what is meant by personalized compared with precision medicine. As new innovations in healthcare are developed, new terminology will undoubtedly also develop. It is critical to continue exploring how patients understand new terms and unintended consequences that may result from misunderstanding.

By definition, precision medicine is a dynamic, multifaceted approach to healthcare, which takes into account complex sets of factors that can influence one's health and well-being (Ashley, 2015; Collins & Varmus, 2015). This study sought to understand patients' perceptions of these multidimensional factors associated with personal health. No one factor emerged as the "most important" determinant of health, indicating wide variation in beliefs among patients. This has important implications for precision medicine initiatives which tend to focus on genetic aspects and argues for the need to give equal emphasis to social, behavioral, and environmental components (Davis & Shanley, 2017). In addition, new provider training initiatives are necessary to help those on the front lines guide patients through behavior and environmental considerations alongside their genetic testing options.

The most prominent difference in perceived drivers of personal health was found in African American/Black participants' higher responses that discrimination and ethnicity/race play an

important role in their personal health. This is consistent with a large body of work highlighting the inequities and discrimination ethnic/racial minority groups often experience in the healthcare system (Dickman et al., 2017; Institute of Medicine, 2003; Williams et al., 2008) and recent research demonstrating the specific role cultural experiences have on precision medicine perceptions (Kraft et al., 2018). While Hispanic/Latino groups also experience health disparities and discrimination within the healthcare system (Dickman et al., 2017; Institute of Medicine, 2003; Williams et al., 2008), in this study, no significant differences were found between Hispanic/Latino and White participants in their perceptions of the role that discrimination and ethnicity/race plays in their personal health. This may be due to different experiences of Hispanic/Latinos in Miami where they constitute a demographic majority. There is also considerable heterogeneity among the Hispanic/Latino population in Miami; thereby, indicating a need for additional research with different Hispanic/Latino groups. Such research can allow providers to be familiar with the unique experiences of the patient populations in their communities when designing and delivering precision medicine services. Findings from our study also highlight the importance of looking at differences across specific ethnic/racial groups instead of conducting white/ minority comparisons in future research.

The results from this study indicate that individuals reflect on many personal values when considering issues related to precision medicine. An understanding of these values is important to the field as patient values have been tied to effective implementation of evidence-based medicine and improved healthcare service engagement (Sackett et al., 1996; Zhang et al., 2017). We asked participants about their values related to genetic testing, one of the most recognizable precision medicine services. Participants supported many values including trust with their provider, privacy, cost, and both receiving their results and having someone help them understand their results. These results speak to the importance of promoting access to genetic counselors as part of precision medicine initiatives given their specific training in addressing many of the values endorsed by participants in this study. While not all clinics have access to genetic testing by having a trusted provider available who will protect the privacy of patients. It is also important to explain to patients the process through which they will receive their results, counseling related to their results, and associated costs.

Our respondents' preferences to receive genetic test results can considered when informing potential research participants about use of their genetic information. A large majority (83.7%) of our sample valued receiving their genetic test results. In the research setting, the prospect of returning potentially clinically relevant information to participants raises issues of appropriate informed consent and how to counsel participants on understanding and using the information. Returning genetic results also poses numerous risks that our respondents may not have considered, including emotional and psychological distress about interpreting results of uncertain significance, genetic discrimination, or financial burdens of seeking medical interventions. Return of genetic information to research participants is practiced with wide variability (Henderson et al., 2014), and a search for consensus recommendations is underway (National Human Genome Research Institute, 2017). Noting the prevalent

desire to receive results among our sample reinforces the challenge for researchers to anticipate when and how to return genetic information to participants with clarity and care.

On the issue of payment when blood or tissue donations are used for research or profit, less than one-quarter (24.6%) of people surveyed felt it was important to receive payment for blood or tissue donation. While this is a minority view, people who consider payment important may be less willing to participate or less satisfied with donating samples for research. African Americans/Blacks in our sample were almost twice as likely as Whites (30.2% versus 16.1%) to report valuing payment for blood and tissue donations. Some of this difference may be related to historical discrimination African Americans/Blacks have experienced in prior research (e.g., United States Public Health Service Syphilis Study at Tuskegee and the Henrietta Lacks case), which has been shown to be related to distrust in precision medicine initiatives (Kraft et al., 2018). Our analysis, however, found that African American/Blacks in our study population did not consider trust to be more important than Whites when deciding to get a genetic test. This result was somewhat surprising given existing literature highlighting the importance of trust in genetic testing and the lower trust in healthcare providers held by African American/Blacks relative to Whites (Halbert et al., 2016). Regardless, researchers and practitioners should continue to explore the cultural and historical background patients may be bring to precision medicine initiatives and design methods to support these varying values.

Study Limitations.

This study has several limitations. First, our sample was recruited from two cities in the U.S. and may not represent patients in other regions of the country. In addition, the education level of our sample was higher compared to the U.S. population (Ryan & Bauman, 2016). This may reflect the fact that our sample was a patient population who consented for a research study (Cobb et al., 2014). Additional research is needed to better understand precision medicine perspectives in other populations. Second, this survey was limited to patients' perspectives about different aspects of precision medicine and did not include specific behaviors related to healthcare utilization. There is a need for more in-depth research examining how knowledge and attitudes related to precision medicine influence how patients seek and experience healthcare. Finally, this survey was designed to broadly explore patient values and factors that may influence health. Future research is needed to understand how these values related to one another (e.g., through ranking and forced choice items) and how that impacts how patients seek and accept services related to precision medicine.

Conclusions

The recent emergence of precision medicine has important implications for patients, providers, and researchers. At present, most patients report low levels of familiarity, with limited differences in perceptions across ethnic/racial groups. Genetic counselors are uniquely positioned to help ensure equitable educational outreach to prevent future ethnic/racial disparities. Culturally sensitive efforts tailored to health literacy level should also

consider individual behavior and environment in parallel to genetic factors to enhance precision medicine uptake for a broader population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table I.

Participant Demographics

| Characteristic | Full Sample (N=252 |
|--|--------------------|
| Site | |
| Vanderbilt University Medical Center | 100 (39.7) |
| Meharry Medical College / Nashville General Hospital | 52 (20.6) |
| University of Miami | 100 (39.7) |
| Age, Mean(SD) | 51.47 (15.29) |
| Sex/Gender | |
| Male | 87 (34.5) |
| Female | 164 (65.1) |
| Other | 1 (0.4) |
| Prefer not to answer | 0 (0) |
| Language of Survey | |
| English | 210 (83.3) |
| Spanish | 42 (16.7) |
| Place of Birth | |
| United States | 168 (66.7) |
| Outside of the United States | 82 (32.5) |
| Missing | 2 (0.8) |
| Highest Educational Level | |
| 8 th grade or less | 3 (1.2) |
| Some high school | 19 (7.5) |
| High school or GED | 45 (17.9) |
| Some college or 2-year degree | 59 (23.4) |
| College graduate | 56 (22.2) |
| More than college degree | 68 (27.0) |
| Health Literacy, Median(IQR) | 13 (11 – 15) |
| Low health literacy (score 9) | 35 (13.9) |
| Adequate health literacy (score 10) | 217 (86.1) |
| Ethnicity/Race | |
| African American / Black ^a | 107 (42.5) |
| Hispanic / Latino | 65 (25.8) |
| White | 63 (25.0) |
| Other ^b | 17 (6.7) |

n (%) except when otherwise noted

^aFour individuals endorsed African American / Black race along with an additional race and were included in the African American / Black group

 $b_{\text{Individuals in the "Other" category endorsed themselves as non-Hispanic (n=17) and either American Indian or Alaska Native (n=1), Asian (n=8), Native Hawaiian or Other Pacific Islander (n=1), checked the "Prefer not to answer" option (n=4), or did not check any of the seven response options for the race question (n=3)$

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Table II.

Familiarity with precision medicine terms

| Onoction: How familiar | ; | | | Ethnic / R | acial Group | s | | | | Health Lit | eracy ^b | |
|---|---------------------------------|---------------|-------------------------------|-----------------------------|-------------------------------|---------------------|----------------------------|-------|-------------------|--------------------------|-----------------------------|---------------------|
| zuestion: trow latinitat are you with the following words or bhrases? ^d | Overall Sample N=252 % | White N=63 | African American/ Black | Hispanic/ Latino N=65 | Africa American/ vs. Wh | un 'Black ite | Hispanic/L vs. White | atino | Low 9 N= 35 | Adequate 10 N= 217 | HLit a continu varial | is a nous ble |
| | | % | N=107 % | % | B(SE) | B | B(SE) | ß | % | % | B(SE) | ß |
| General | | | | | | | | | | | | |
| Precision medicine | 23.8 | 15.9 | 23.6 | 28.1 | .39(.23) | .14 | .23(.37) | .07 | 20.0 | 24.7 | .12(.04) | .22 |
| Personalized medicine | 37.3 | 39.7 | 32.7 | 42.9 | .02(.23) | .01 | .03(.38) | .01 | 34.3 | 38.7 | .09(.04) | .17 |
| Genetics | | | | | | | | | | | | |
| Gene | 63.9 | 73.0 | 61.7 | 52.3 | 04(.20) | 02 | 15(.33) | 05 | 34.3 | 68.7 | .16(.04) | .30* |
| Genomics | 32.9 | 48.4 | 26.7 | 23.8 | 41(.22) | -14 | -22(.36) | -07 | 18.2 | 36.0 | .10(.04) | .18 |
| DNA | 71.0 | 82.3 | 71.7 | 60.3 | .02(.19) | .01 | -40(.31) | -15 | 48.6 | 76.1 | .13(.04) | .28 |
| Chromosome | 58.7 | 71.4 | 52.3 | 54.7 | -13(.20) | -05 | -17(.33) | 90- | 34.3 | 63.0 | .13(.04) | .25 |
| Hereditary | 67.5 | 79.4 | 61.9 | 68.3 | -12(.20) | -05 | -15(.34) | -05 | 44.1 | 72.8 | .11(.04) | .21 |
| Biobank | 17.9 | 12.7 | 18.1 | 20.3 | .25(.21) | 60. | -24(.35) | -08 | 5.9 | 20.0 | .11(.04) | .21 |
| Genetic testing | 56.3 | 66.7 | 50.5 | 54.0 | -15(.21) | -06 | 12(.34) | -04 | 35.3 | 60.2 | .13(.04) | .24 |
| Biological indicators | 37.3 | 42.9 | 35.5 | 28.1 | -05(.23) | -02 | -37(.38) | -11 | 14.3 | 41.4 | .15(.04) | .26* |
| Biomarkers | 24.9 | 33.3 | 18.9 | 18.8 | -26(.21) | 60- | -30(.35) | -10 | 11.4 | 27.1 | .12(.04) | .22 |
| Pharmacogenomics | 19.0 | 17.7 | 12.4 | 26.6 | .03(.20) | .01 | .05(.33) | .02 | 8.8 | 21.0 | .12(.04) | .23 |
| Lifestyle & Environment | | | | | | | | | | | | |
| Social determinants of health | 29.0 | 25.4 | 26.4 | 29.7 | .21(.21) | .08 | .18(.34) | .06 | 17.1 | 31.2 | .10(.04) | .19 |
| 3 | | | | | | | | | | | | |

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p. .003 (Bonferroni correction) in adjusted analyses including covariates place of birth, survey language, and education

^aIn multivariable analyses, outcome variables were treated as continuous. This table dichotomizes the outcome variables (percentages reflect those reporting themselves to be either "extremely" or "moderately" familiar with each term) for ease of interpretation.

 $b_{\rm III}$ multivariable analyses health literacy was treated as a continuous level predictor. This table dichotomizes the health literacy variable for ease of interpretation.

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Table III.

Perceptions of factors associated with personal health

| | : | | | Ethnic / R | tacial Group | s | | | | Health L | iteracy ^b | |
|--|---------------------------------|---------------|-------------------------------|-----------------------------|-------------------------------|-------------------|----------------------------|-------|-------------------|--------------------------|-----------------------------|------------------|
| Question: How much do each of these affect your health? ^a | Overall Sample N=252 % | White N=63 | African American /Black | Hispanic/ Latino N=65 | Africa American/ vs. Wh | n Black ite | Hispanic/I vs. White | atino | Low 9 N= 35 | Adequate 10 N= 217 | HLit a continu variab | s a ous de |
| | | % | N=10/ % | % | B(SE) | đ | B(SE) | ß | % | % | B(SE) | g |
| Cultural Background | | | | | | | | | | | | |
| My race or ethnicity | 19.4 | 11.3 | 29.2 | 11.1 | .83(.21) | .31 | 06(.35) | 02 | 21.2 | 19.1 | 05(.04) | -10 |
| My culture | 26.2 | 22.2 | 32.7 | 17.5 | .43(.22) | .15 | 44(.37) | 14 | 18.2 | 28.0 | -03(.04) | -05 |
| My ability to speak English | 30.2 | 33.3 | 34.9 | 19.4 | .09(.25) | .03 | 93(.41) | -27 | 38.2 | 29.4 | 05(.05) | 60- |
| Discrimination | 13.5 | 3.2 | 20.6 | 14.3 | 1.0(.19) | .40* | .23(.32) | .08 | 21.2 | 12.5 | -06(.04) | -12 |
| Genetics | | | | | | | | | | | | |
| The health problems that run in my family | 31.7 | 28.6 | 36.5 | 30.6 | .35(.21) | .13 | 21(.35) | 07 | 30.3 | 32.9 | 05(.04) | -10 |
| My genes/genetics | 24.6 | 29.0 | 27.6 | 16.1 | .05(.22) | .02 | 32(.36) | 11 | 6.3 | 28.2 | 02(.04) | -03 |
| Health Literacy | | | | | | | | | | | | |
| My ability to understand what I need to do to stay healthy | 36.5 | 46.8 | 35.2 | 26.6 | 10(.25) | 03 | -85(.40) | 25 | 29.4 | 38.3 | 09(.05) | -16 |
| Socio-economic Status | | | | | | | | | | | | |
| My income/family income | 25.4 | 24.2 | 27.1 | 26.2 | .22(.20) | 60. | 17(.33) | 06 | 30.3 | 25.2 | 02(.04) | -05 |
| My education | 25.8 | 31.1 | 22.4 | 23.8 | .10(.22) | .04 | 89(.35) | 30 | 20.6 | 27.1 | 03(.04) | 06 |
| My insurance status | 33.7 | 32.3 | 35.2 | 33.9 | .25(.23) | 60. | 20(.38) | 06 | 30.3 | 35.2 | 07(.05) | 12 |
| My occupation | 21.8 | 19.0 | 22.1 | 23.8 | .28(.22) | .10 | 01(.36) | .00 | 21.9 | 22.3 | 06(.04) | 12 |
| | | | | | | | | | | | | |
| The community where I live | 15.5 | 7.9 | 20.6 | 9.5 | .34(.20) | .14 | 45(.32) | 16 | 11.8 | 16.2 | 06(.04) | 12 |

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* .004 (Bonferroni correction) in adjusted analyses including covariates place of birth, survey language, and education

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 $b_{\rm III}$ multivariable analyses health literacy was treated as a continuous level predictor. This table dichotomizes the health literacy variable for ease of interpretation.

Table IV.

Values considered important when deciding to get a genetic test

| Question: How important | | | | Ethnic / R | tacial Group | s | | | | Health Lit | eracy ^b | |
|---|---------------------------------|---------------|-------------------------------|-----------------------------|--------------------------------|-------------------|----------------------------|-------|-------------------|--------------------------|-----------------------------|------------------|
| are the following to you when making a decision about getting a genetic | Overall Sample N=252 % | White N=63 | African American /Black | Hispanic/ Latino N=65 | Africa American/ vs. Whi | n Black ite | Hispanic/I vs. White | atino | Low 9 N= 35 | Adequate 10 N= 217 | HLit a continu variab | s a ous le |
| test? | | % | N=10/ % | % | B(SE) | ß | B(SE) | ß | % | % | B(SE) | ß |
| Trust in my doctor, nurse practitioner, etc. | 77.4 | 87.1 | 73.8 | 76.9 | 09(.18) | 04 | .00(.30) | .00 | 65.7 | 79.6 | .11(.04) | .24 * |
| Cost of the test | 63.9 | 56.5 | 71.0 | 61.3 | .17(.21) | .07 | .40(.34) | .14 | 61.8 | 65.7 | .04(.04) | .08 |
| Receiving payment for my blood or tissue donation (if my donation will be used for research or profit) | 24.6 | 16.1 | 30.2 | 23.0 | .74(.23) | .26* | .83(.39) | .25 | 33.3 | 23.9 | 05(.05) | 10 |
| Receiving the results of my genetic test | 83.7 | 88.7 | 82.1 | 85.7 | 09(.16) | 05 | .31(.26) | .14 | 79.4 | 86.0 | .06(.03) | .14 |
| Receiving counseling about my test results | 74.2 | 71.0 | 72.6 | 82.3 | .24(.19) | .11 | .33(.30) | .13 | 67.6 | 77.0 | .09(.04) | .19 |
| That my results will be kept private | 79.4 | 85.5 | 81.0 | 80.3 | 04(.19) | 02 | 03(.32) | 01 | 75.8 | 82.9 | .07(.04) | .16 |
| * | | | | | | | | | | | | |

p .008 (Bonferroni correction) in adjusted analyses including covariates place of birth, survey language, and education

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^aIn multivariable analyses, outcome variables were treated as continuous. This table dichotomizes the outcome variables (percentages reflect those endorsing each item as either "extremely" or "very" important) for ease of interpretation.

b multivariable analyses health literacy was treated as a continuous level predictor. This table dichotomizes the health literacy variable for ease of interpretation.