Ethnic identity and engagement with genome sequencing research

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Abstract

Purpose.—We examined the role of ethnic identity (which measures the degree to which individuals identify with their ethnic group) in beliefs about, and intentions to learn, genomic results.

Methods.—A longitudinal cohort was recruited to implement genome sequencing among healthy participants self-identifying as African, African-American, or Afro-Caribbean, 40–65 years old (n=408). Before receiving genomic results, participants completed a survey assessing social and behavioral constructs related to health, genomics, and ethnic identity.

Results.—Ethnic identity was positively correlated with perceived value of genomic results and expected benefits from genomic research participation. Among participants with stronger ethnic identity, cognitive beliefs [perceived value of results (b=0.63, 95% CI: 0.29, 0.98, p<0.001) and expected benefits from genomic research participation (b=0.32, 95% CI: 0.12, 0.53, p=0.002)] were associated with intentions to receive results. Among those with weaker ethnic identity, there was no such association.

Conclusion.—Individuals with stronger ethnic identity seem to attend more to cognitive beliefs such as the value of genomic results when deliberating receipt of results compared to those with weaker ethnic identity. Understanding ethnic identity variation and its influence on genome sequencing perceptions and intentions can inform future research opportunities using ethnic identity to explore specific practical, clinical questions.

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Keywords

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Introduction

With evidence of disparities in genomic testing and research among racial and ethnic groups[1, 2] there is a critical need to better understand the experiences of diverse participants in genomic research, that is, studies involving exome/genome sequencing. At the group level (e.g., European-American compared to African-American), African-Americans have lower awareness, and fewer positive and more negative attitudes about genetic testing.[3] There are racial and ethnic group differences in how individuals respond to genetic information, such as discussing results with family and changing health behaviors.[4] Although these studies have yielded important findings at the group level, it is necessary to investigate heterogeneity within groups.

In a healthcare context, aligned with federal guidelines,[5] ethnicity is defined solely as "Hispanic or Latino" and "not Hispanic or Latino". In common usage, however, ethnicity is a social categorization, defined by a wide variety of factors including culture, heritage, or national origin.[6] In contrast, race is mostly aligned with continental origin. The term 'racial identity' has some overlap, but in other contexts is distinct from ethnic identity. Evidence suggests both race and ethnicity, regardless of how they are defined, relate to health disparities.[7] Here we combine those constructs into a single attribute called ethnicity.

The degree to which individuals identify with their ethnic group is a quantifiable trait. The multigroup ethnic identity measure (MEIM) is a tool used to measure this trait. MEIM captures ethnic identity by asking participants questions that relate to knowledge about membership in one's ethnic group and the value and emotional significance related to that membership.[8] Note that ethnicity in the MEIM parallels the definition used in our study. Among African-Americans, measures of ethnic identity have been shown to be correlated with more adaptive health behaviors and outcomes such as lower blood pressure,[9] reduced drug use,[10] and higher levels of exercise.[11] Ethnic identity appears to affect health behaviors via the buffering of stress and resulting health consequences of discrimination.[12, 13] However, evidence in the health context is limited, and a contradictory theory posits that strong ethnic identity may intensify stress from discrimination.[14]

As the field of genomics moves toward increasing numbers of participants from minority ethnic groups, investigators must be mindful of the heterogeneity within ethnic groups in order to promote multicultural practices.[15] Further, acknowledgement of such heterogeneity may mitigate over-generalizations or the adoption of 'one-size-fits-all' approaches that could result in further disparities across ethnic groups. Prior research in one genetic testing study found an association between ethnic identity and perceptions about genetic testing; among African-American women, ethnic identity was found to be positively related to perceived benefits of genetic testing for cancer risk.[16] Studying heterogeneity in terms of ethnic identity in the context of genomic research may add to our understanding of the experiences of minority ethnic groups in genomic research studies.

The common-sense model (CSM) of self-regulation has been applied to aid understanding about perceptions, preferences, and behavior in relation to genetic test results.[17] This theory recognizes the importance of both cognitive and affective beliefs about health information in determining what people want to learn about their health and the actions they take with that information. The CSM has been widely used to study health behavior, most often in predominantly European populations, though to a limited degree among minority ethnic groups. For example, a study of New Zealanders with diabetes found that illness beliefs were associated with health behaviors in different ways, depending on ethnic group (Pacific Islanders compared to Europeans).[18] Although a causal link between ethnic identity and illness beliefs has not been elucidated, understanding how variation within ethnic groups (for example ethnic identity) interacts with the CSM constructs could contribute to understanding the origin of these group differences.

To our knowledge, no prior study has investigated ethnic identity among African-American individuals participating in genomic research. At the group level, available evidence and theory are mixed, suggesting that variation in ethnic identity within groups could be positively or negatively related to interest and beliefs about genomic research. For example, compared to European-Americans, African-Americans have higher intentions to discuss their genetic test results with family members, suggesting that ethnic identity could contribute positively to interest in and beliefs about genomic results.[4] In contrast, ethnic identity may have a negative effect on beliefs and intentions about genomic information, given the historical context of African-Americans in genetic research and medical research more generally.[19, 20] For example, those with stronger ethnic identity may be more skeptical of the value of genomic results and thus have lower intentions to receive such information. Two prior studies found that the proportion of individuals who choose not to receive genomic results is higher in African-Americans as compared to European-Americans.[21, 22]

In this study, we evaluated the relationship of ethnic identity to cognitive and affective beliefs about genomic research and how these constructs may be associated with intentions to learn genomic results. Cognitive beliefs included perceptions about the value of genomic results and the expected benefits and harms from genomic research participation.[17] For affective beliefs, we studied affective risk perception, which is also conceptualized as how worried individuals are about their risk of having a genetic condition.[23]

Considering both the theoretical evidence above, and the aforementioned empirical evidence showing the association of ethnic identity and perceived benefits of genetic testing for cancer risk,[16] we hypothesized that stronger ethnic identity is associated with more positive beliefs about genomic research. We further hypothesized that higher ethnic identity strengthens the relationship of beliefs with intentions to learn genomic results.

Methods

Participants and procedures

ClinSeq®, a longitudinal exome sequencing study, has been conducted at NIH for over a decade.[24] Participants do not necessarily enroll to learn sequencing results, although are informed they may have an opportunity to learn health-related results throughout the

duration of the study. Early recruitment efforts resulted in a cohort of 1,001 predominantly European-American, well-educated, and mostly healthy participants, although the cohort was oversampled for individuals at risk of cardiovascular disease.[25] In 2011, efforts began to recruit a more diverse sample, resulting in recruitment of 467 healthy participants who self-identified as African, African-American or Afro-Caribbean.[26] Participants were ages 40–64 at the time of consent, non-smokers over the past year, and lived in the Washington DC metro area.

Recruitment from 2011 onwards was coordinated by a full-time African-American outreach coordinator. Passive recruitment strategies included posting flyers in businesses and advertisements on radio stations. The most common active recruitment strategies included in-person recruitment at health fairs and church groups. Individuals who were interested in participating gave their information to the outreach coordinator who contacted these individuals for eligibility screening. If eligible for the study, participants gave consent and subsequently were invited to complete a baseline survey (before receiving any sequencing results) with a range of social and behavioral constructs related to genomic research.[26] Surveys were completed on-line, on paper, or verbally during the enrollment session whereby a staff member entered responses into an electronic format. The National Human Genome Research Institute IRB approved the parent study.

Measures

Ethnic identity was assessed using the MEIM.[8] The mean of 12 items was computed for a total MEIM score. Example items included: "I have a strong sense of belonging to my own ethnic group." and "I have a lot of pride in my racial/ethnic group." On a 4-point scale, responses ranged from strongly disagree (1) to strongly agree (4). Higher scores indicate a stronger ethnic identity. Cronbach's alpha was 0.81.

Perceived value of genomic results was measured through a previously published three-item scale.[27] The items had the stem "my sequencing results will be…" and consisted of the following: "valuable for maintaining my future health", "valuable for maintaining my family's future health" and "useful to my physician". Response options appeared on a 5-point scale from strongly disagree (1) to strongly agree (5). The mean of the three items was used for the total score. Higher scores indicated higher perceived value of sequencing results. Cronbach's alpha was 0.80.

Expected benefits from genomic research participation were collected through two items adapted from a previously published scale[28] with the stem "please rank how likely the following outcomes are from learning your sequence results" followed by "how likely is it that you will experience…" The two items were "health benefits from learning sequence results?" and "health benefits from receiving standard medical care?" Response options were a seven-point scale from extremely unlikely (1) to extremely likely (7). Total scores were the mean of these two items. Correlation between the two items was 0.50, $p<0.001$.

Expected harms from genomic research participation were collected through two items with the stem "please rank how likely the following outcomes are from learning your sequence results" followed by "how likely is it that you will experience…". The two items were

"health harms from learning sequence results?" and "health harms from receiving standard medical care?" Response options were a seven-point scale from extremely unlikely (1) to extremely likely (7). Total scores were the mean of these two items. Correlation between the two items was 0.70, $p<0.001$.

Affective risk perception was measured by computing the mean of two items where participants indicated how worried they were about the following outcomes: "that your genes put you at increased risk for developing a common chronic disease, like cancer or heart disease" and "that you already have a health condition that was caused primarily by your genes." Responses were given on a seven-point scale from not at all worried (1) to extremely worried (7). Correlation between the two items was 0.73, $p<0.001$.

Intentions to receive genomic results were assessed by two items. The first item referred to *actionable* disease risk results: "by participating in the ClinSeq® study and having your genome sequenced you could learn about a gene variant that predisposes you to a disease that can be prevented or treated. How likely is it that you will choose to learn about such as result?". The second item referred to *non-actionable* disease risk results: "by participating in the ClinSeq® study and having your genome sequenced you could learn about a gene variant that predisposes you to a disease that cannot be prevented or treated. How likely is it that you will choose to learn about such as result?". Intentions were collected on a seven-point scale from extremely unlikely (1) to extremely likely (7). We asked about "expected likelihood" as this phrasing is more predictive of actual behavior than directly asking about "intentions".[29]

Co-variates tested in the moderation analyses included the following participant characteristics: age, sex, education level, and income.

Analysis

We calculated descriptive statistics of participant characteristics and main measures. Bivariate analyses (Pearson correlation for continuous participant characteristics, one-way ANOVA for categorical characteristics) were used to test the association of participant characteristics with MEIM. Main effects were tested with Pearson correlations for normal data, and Spearman correlations for non-normal data, controlling for any participant characteristics that were significant in bivariate analyses. A Holm-Bonferroni correction was applied to control for familywise error.

We investigated whether ethnic identity moderated the relationship of the independent variables: (1) perceived value of genomic results, (2) expected benefits, (3) expected harms, and (4) affective risk perception; with the outcome variables: (1) intentions to receive actionable disease risk results and (2) intentions to receive non-actionable disease risk results. SPSS software facilitated analyses (SPSS Inc. Released 2012. SPSS for Mac, Version 21.0. Chicago, SPSS Inc.). The PROCESS plug-in was used for moderation analyses.[30] We used Model 1 (for moderation analysis) to estimate the conditional indirect effects for the mean +/– one *SD* of the moderator (MEIM). This model mean centers the variables and uses bias-corrected bootstrap confidence intervals with 5,000 bootstrap samples. To conduct post hoc probing of MEIM as a moderator and to plot moderator

effects, a dummy code variable was created to compare three levels of MEIM. The discrete values were low (1 *SD* below the mean), average (the mean) and high (1 *SD* above the mean).

Results

Descriptive results

The majority of the participants were female (75.0%) and educated at the college level or beyond (65.4%). Of the 408 participants, 37% had an annual household income of over $100,000. Participants ranged in age from 43 to 72 years at the time of completing the survey. Descriptive statistics for participant characteristics and all measures appear in Table 1.

Main effects

Among the demographics tested, ethnic identity was positively associated with older age (r=0.20, p<0.001) and higher level of education [F(5, 362) = 6.26, p<0.001].

As hypothesized, strong ethnic identity was associated with high perceived value of genomic results (r=0.204, p=0.0003) and expectations for benefits from genomic research participation (r=0.177, p=0.002). Although strong ethnic identity was negatively associated with expectations for harms from genomic research participation, this association was not conventionally significant when controlling for age and education. MEIM was not associated with affective risk perception (r=0.076, p=0.02). (Table 2)

Moderating role of ethnic identity

Independent variable: perceived value of genomic results—Overall, there was a significant interaction between MEIM and perceived value of genomic results for intentions to learn actionable (b=0.68, 95% CI: 0.28, 1.08, p=0.0008) or non-actionable (b=0.55, 95% CI: 0.12, 1.00, p=0.015) disease results.

Among participants with stronger ethnic identity (1 *SD* above the mean), there was a positive association of perceived value of genomic results with intentions to receive results for both actionable (b=0.63, 95% CI: 0.29, 0.98, p=0.0003) and non-actionable disease (b=0.79, 95% CI: 0.38, 1.20, p=0.0002). The pattern was the same for participants with average ethnic identity: there was a positive association of perceived value of genomic results with intentions to receive results for both actionable (b=0.28, 95% CI: 0.036, 0.51, p=0.02) and non-actionable disease (b=0.50, 95% CI: 0.21, 0.79, p=0.0007).

In contrast, among participants with weaker ethnic identity (1 *SD* below the mean), there was no association of perceived value of genomic results and intentions to learn actionable (b=−0.084, 95% CI: −0.37, 0.21, p=0.57) or non-actionable (b=0.21, 95% CI: −0.11, 0.53, p=0.20) disease results. (Figure 1)

Independent variable: expected benefits from genomic research participation—Similarly, there was a significant interaction between MEIM and expected benefits from

genomic research participation for intentions to learn actionable (b=0.29, 95% CI: 0.04, 0.54, p=0.02) or non-actionable (b=0.17, 95% CI: 0.02, 0.08, p=0.001) disease results.

As above, among participants with stronger ethnic identity, there was a positive association of expected benefits with intentions to receive results for actionable (b=0.32, 95% CI: 0.12, 0.53, p=0.002) and non-actionable disease (b=0.29, 95% CI: 0.07, 0.52, p=0.01). Among participants with average ethnic identity there was also a positive association of perceived value of genomic results with intentions to receive results for both actionable (b=0.17, 95% CI: 0.031, 0.31, p=0.02) and non-actionable disease (b=0.17, 95% CI: 0.02, 0.33, p=0.03).

Among participants with weaker ethnic identity, however, there was no association of expected benefits with intentions to learn actionable (b=0.02, 95% CI: −0.16, 0.20, p=0.84) or non-actionable (b=0.05, 95% CI: −0.14, 0.24, p=0.61) disease results. (Figure 2)

Independent variable: expected harms from genomic research participation—
Overall, the interaction between MEIM and expected harms from genomic research participation was not conventionally significant for intentions to learn actionable (b=−0.10, 95% CI: −0.06, 0.003, p=0.07) or non-actionable (b=−0.09, 95% CI: −0.07, 0.004 p=0.08) disease results.

Although the interaction was not significant overall, there was a similar pattern as for other cognitive beliefs, MEIM and intentions. Among participants with stronger ethnic identity, there was a negative association of expected harms with intentions to receive results for actionable (b=−0.17, 95% CI: −0.32, −0.020, p=0.03 or non-actionable disease (b=−0.19, 95% CI: −0.37, −0.0062, p=0.04). Among participants with average ethnic identity there was a negative association of expected harms and intentions to receive results for actionable disease (b=−0.11, 95% CI: −0.22, −0.0086, p=0.03), though no association of expected harms and intentions to receive results for non-actionable disease ((b=−0.12, 95% CI: −0.24, 0.0008, p=0.05).

Again, among those with weaker ethnic identity, there was no association of expected harms and intentions to learn actionable (b=−0.05, 95% CI: −0.18, 0.090, p=0.50) or non-actionable (b=−0.066, 95% CI: −0.22, 0.085, p=0.39) disease results. (Figure 3)

Independent variable: affective risk perception—Ethnic identity did not moderate the association of affective risk perception with intentions. (Figure S1)

Discussion

In our study of US individuals of African descent in a genomic research study we found that ethnic identity was positively associated with perceived value of results and expected benefits from participation in such a study. Importantly, these beliefs about the value and benefits were associated with intentions to receive results only among those with average-to-strong ethnic identity, and not among those with weak ethnic identity. Ethnic identity has been found to be related to a variety of health outcomes,[12] consistent with our findings. It is thought that ethnic identity has a positive impact on health outcomes through buffering the stress of discrimination, though the process is not well understood. It is possible that

identifying with a particular ethnic group provides individuals with an understanding that negative stereotypes result from societal injustices, thus allowing individuals to avoid personally internalizing those negative stereotypes.[31]

Prior research has focused on comparing beliefs about genetics and genomics at the group level, and suggests that African-Americans have less positive beliefs as compared to European-Americans.[3, 4] However, our results suggest the link between ethnicity and beliefs may be more nuanced due to the presence of within-group heterogeneity. The only previous study offering genetic testing to participants that investigated ethnic identity and perceptions about genetic testing reported similar findings. They found that African-American individuals with stronger ethnic identity perceived more benefits about genetic testing for cancer risk.[16] In addition to replicating these findings in a larger sample and different testing context, our moderation analyses extend these findings, suggesting that compared to those with weak ethnic identity, those with average-to-strong ethnic identity attend to cognitive beliefs such as the value of results and benefits of genomic testing when deliberating whether to receive both actionable and non-actionable results. Among those with lower ethnic identity, there may be unmeasured variables that have more important influence on intentions to receive results in a genomic research study. For example, unmeasured variables could include benefits and harms to African-Americans more broadly. While this was outside the scope of our study, which focused on personal benefits and harms and receipt of results, qualitative data suggest some members of our cohort were motivated to enroll to counter underrepresentation from minority populations in genomics research.[26]

Although others have reported associations between affective risk perceptions and health behavior and intentions,[32, 33] we did not identify an association here with intentions to learn results, nor did ethnic identity have a moderating role in the association of affective risk perceptions with these intentions. This perhaps represents a difference in the link between affective risk perceptions and health behaviors among African-Americans as compared to prior studies of predominantly European-Americans. Indeed, others have found at the group level that cancer worry is associated with more frequent breast self-examinations among European American and English-speaking Caribbean women, whereas the association was not detected for African-American women.[34] Taken together, our results suggest that the association of both cognitive and affective beliefs with engagement in genomic research as posited by the CSM may not be consistent across individuals with different ethnic identities.

The results of our study should be interpreted in light of limitations. The sample was more highly educated than the overall U.S. population of people of African descent which may affect generalizability of our results. Overall, participants' intentions to receive actionable results were skewed; however, our sample likely has higher intentions and more positive attitudes about genome sequencing compared to the general population given they possess some of the characteristics of early adopters.[26] We expect intentions to receive actionable results are more varied among the general population, which may in fact strengthen the findings we observed here. The measures in this study have largely not been validated with African-Americans which may account for the lack of associations (e.g., expected harms and affective risk perception). Although the patterns from our analyses are consistent with our hypotheses, future work is needed to determine how to appropriately measure these

constructs in diverse populations. Lastly, the cross-sectional nature of our study limits the interpretation of the associations of our findings, and actual health behavior and decisions were not assessed. Follow-up studies with this sample are planned and will allow us to better understand ethnic identity and health behaviors in genomics. Despite these limitations, strengths include the composition of our sample, including a sizeable number of individuals of African descent as compared to prior studies, and collection of a unique combination of variables (cognitive and affective beliefs, intentions, and MEIM).

Clinical and research implications

Our results contribute to ongoing efforts to develop genetic testing processes and materials that are culturally sensitive[15, 35] and to recent discourse about the importance of conducting genomic research in diverse populations.[36, 37] In considering this evolution towards multiculturalism in genomic research, it is crucial to consider the heterogeneity among ethnic groups, rather than adopting universal approaches to multicultural practices.

While direct clinical benefits from our work are limited at this time, our findings can be used to frame specific questions to test in future research. Interventions tailored to particular racial or ethnic groups have been studied in genetics.[38, 39] Consideration of the heterogeneity within groups should be a focus of future work given our study findings. For example, in collaboration, genetics researchers and social and behavioral scientists designing interventions for genomic result disclosure and education may consider the role of ethnic identity. Drawing from research in a different health context, there is a moderating effect of ethnic identity in participants' responses to culturally-targeted interventions to increase colorectal cancer screening rates.[40] This prior work shows that those with lower ethnic identity would respond more strongly to positively framed messages (e.g., "by participating in recommended screening you could remain free from cancer…") whereas those with higher ethnic identity would respond more strongly to negatively framed messages (e.g., by not participating in recommended screening you could neglect a treatable cancer…") We hypothesize a similar moderating role of ethnic identity in message framing about genomics. Although it is outside the scope of a team consisting only of genetics researchers and clinicians, it may be feasible through partnering with social and behavioral scientists for genetics research teams to consider the role of ethnic identity when designing genomic research study materials. In particular, for materials to explain and disclose actionable results, ethnic identity may interact with decisions to receive actionable results and subsequent preventive behaviors.

Though somewhat more challenging, it may be possible to design interventions that foster strong ethnic identity – given that ethnic identity may not be a static phenomenon[8] – thus strengthening the association of cognitive beliefs with participants' intentions. Future work could investigate return of ancestry results to participants and the potential to positively influence ethnic identity. This was not explored in the study reported here as only 6% of our sample indicated having previously received ancestry results, though this hypothesis may be tested in the future given the longitudinal design of our project which involves periodic return of results from a variety of categories.

In conclusion, our results emphasize the importance of within-group variation, and the associations of ethnic identity with various psychosocial genomic concepts. In addition, our findings highlight that investigators recruiting participants from diverse backgrounds should consider the influence of ethnic identity on participants' cognitive beliefs about genomic research participation and their intentions to receive medically actionable and non-actionable disease results.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

REFERENCES

1. Kaphingst KA and Goodman MS, Importance of race and ethnicity in individuals' use of and responses to genomic information. Personalized Medicine, 2016 13(1): 1–4. [PubMed: 29749865]

2. Hall M and Olopade OI, Confronting genetic testing disparities: knowledge is power. Jama, 2005 293(14): 1783–1785. [PubMed: 15827320]

3. Hann KE, Freeman M, Fraser L, Waller J, Sanderson SC, Rahman B, Side L, Gessler S, and Lanceley A, Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review. BMC Public Health, 2017 17(1): 503–533. [PubMed: 28545429]

4. Kaphingst KA, Stafford JD, McGowan LDA, Seo J, Lachance CR, and Goodman MS, Effects of racial and ethnic group and health literacy on responses to genomic risk information in a medically underserved population. Health Psychology, 2015 34(2): 101–110. [PubMed: 25622080]

5. Management, O.o. and Budget, Revisions to the standards for the classification of federal data on race and ethnicity. Federal Register, 1997 62(210): 58782–58790.

6. Kaplan JB and Bennett T, Use of race and ethnicity in biomedical publication. Jama, 2003 289(20): 2709–2716. [PubMed: 12771118]

7. Eisenhower A, Suyemoto K, Lucchese F, and Canenguez K, "Which box should I check?": examining standard check box approaches to measuring race and ethnicity. Health Services Research, 2014 49(3): 1034–1055. [PubMed: 24298894]

8. Phinney JS, The multigroup ethnic identity measure: A new scale for use with diverse groups. Journal of Adolescent Research, 1992 7(2): 156–176.

9. Scribner R, Hohn A, and Dwyer J, Blood pressure and self-concept among African-American adolescents. Journal of the National Medical Association, 1995 87(6): 417–422. [PubMed: 7595963]

10. Brook JS and Pahl K, The protective role of ethnic and racial identity and aspects of an Africentric orientation against drug use among African American young adults. The Journal of Genetic Psychology, 2005 166(3): 329–345. [PubMed: 16173675]

11. Smalley KB, Warren JC, McClendon S, Peacock W, and Caro M, Ethnic Identity Attachment and Motivation for Weight Loss and Exercise among Rural, Overweight, African-American Women. Clinical Medicine Insights: Women's Health, 2016 9(s1): 95–101.

12. Mossakowski KN, Coping with perceived discrimination: Does ethnic identity protect mental health? Journal of Health and Social Behavior, 2003 44(3): 318–331. [PubMed: 14582311]

13. Ikram UZ, Snijder MB, de Wit MA, Schene AH, Stronks K, and Kunst AE, Perceived ethnic discrimination and depressive symptoms: the buffering effects of ethnic identity, religion and

ethnic social network. Social Psychiatry and Psychiatric Epidemiology, 2016 51(5): 679–688. [PubMed: 26873614]

14. Phinney JS, Ethnic identity and self-esteem: A review and integration. Hispanic Journal of Behavioral Sciences, 1991 13(2): 193–208.

15. Ota Wang V, Multicultural genetic counseling: then, now, and in the 21st century. American Journal of Medical Genetics Part A, 2001 106(3): 208–215.

16. Sussner K, Edwards T, Thompson H, Jandorf L, Kwate N, Forman A, Brown K, Kapil-Pair N, Bovbjerg D, and Schwartz M, Ethnic, racial and cultural identity and perceived benefits and barriers related to genetic testing for breast cancer among at-risk women of African descent in New York City. Public Health Genomics, 2011 14(6): 356–370. [PubMed: 21540561]

17. Cameron LD and Reeve J, Risk perceptions, worry, and attitudes about genetic testing for breast cancer susceptibility. Psychology and Health, 2006 21(2): 211–230. [PubMed: 21985118]

18. Bean D, Cundy T, and Petrie KJ, Ethnic differences in illness perceptions, self-efficacy and diabetes self-care. Psychology and Health, 2007 22(7): 787–811.

19. Adams I, Christopher J, Williams KP, and Sheppard VB, What black women know and want to know about counseling and testing for BRCA1/2. Journal of Cancer Education, 2015 30(2): 344–352. [PubMed: 25301325]

20. Gamble VN, Under the shadow of Tuskegee: African Americans and health care. American Journal of Public Health, 1997 87(11): 1773–1778. [PubMed: 9366634]

21. Fiallos K, Applegate C, Mathews DJ, Bollinger J, Bergner AL, and James CA, Choices for return of primary and secondary genomic research results of 790 members of families with Mendelian disease. European Journal of Human Genetics, 2017 25(5): 530–537. [PubMed: 28272539]

22. Yu JH, Crouch J, Jamal SM, Tabor HK, and Bamshad MJ, Attitudes of African Americans toward return of results from exome and whole genome sequencing. American Journal of Medical Genetics Part A, 2013 161(5): 1064–1072.

23. Ferrer RA, Taber J, Klein W, Harris P, Lewis K, and Biesecker L, The role of current affect, anticipated affect and spontaneous self-affirmation in decisions to receive self-threatening genetic risk information. Cognition and Emotion, 2015 29(8): 1456–1465. [PubMed: 25482843]

24. Biesecker LG, Mullikin JC, Facio FM, Turner C, Cherukuri PF, Blakesley RW, Bouffard GG, Chines PS, Cruz P, and Hansen NF, The ClinSeq Project: piloting large-scale genome sequencing for research in genomic medicine. Genome Research, 2009 19: 1665–1674. [PubMed: 19602640]

25. Lewis KL, Hooker GW, Connors PD, Hyams TC, Wright MF, Caldwell S, Biesecker LG, and Biesecker BB, Participant use and communication of findings from exome sequencing: a mixed-methods study. Genetics in Medicine, 2015 18(6): 577–83. [PubMed: 26540156]

26. Lewis KL, Heidlebaugh AR, Epps S, Han PKJ, Fishler KP, Klein WMP, Miller Ilana M., Ng D, Hepler C, Biesecker Barbara B., and Biesecker LG, Knowledge, motivations, expectations, and traits of an African, African-American, and Afro-Caribbean sequencing cohort. Genetics in Medicine, 2018 in press.

27. Turbitt E, Roberts MC, Ferrer RA, Taber JM, Lewis KL, Biesecker LG, Biesecker BB, and Klein WM, Intentions to share exome sequencing results with family members: exploring spousal beliefs and attitudes. European Journal of Human Genetics, 2018 26: 735–739. [PubMed: 29476166]

28. Weinfurt KP, Castel LD, Li Y, Sulmasy DP, Balshem AM, Benson AB, Burnett CB, Gaskin DJ, Marshall JL, and Slater EF, The correlation between patient characteristics and expectations of benefit from Phase I clinical trials. Cancer, 2003 98(1): 166–175. [PubMed: 12833469]

29. Armitage CJ, Norman P, Alganem S, and Conner M, Expectations are more predictive of behavior than behavioral intentions: Evidence from two prospective studies. Annals of Behavioral Medicine, 2015 49(2): 239–246. [PubMed: 25623893]

30. Hayes AF, PROCESS: A versatile computational tool for observed variable mediation, moderation, and conditional process modeling. 2012, University of Kansas, KS.

31. Pascoe EA and Richman L. Smart, Perceived discrimination and health: a meta-analytic review. Psychological Bulletin, 2009 135(4): 531–554. [PubMed: 19586161]

32. Hay JL, McCaul KD, and Magnan RE, Does worry about breast cancer predict screening behaviors? A meta-analysis of the prospective evidence. Preventive Medicine, 2006 42(6): 401–408. [PubMed: 16626796]

33. Persoskie A, Ferrer RA, and Klein WM, Association of cancer worry and perceived risk with doctor avoidance: an analysis of information avoidance in a nationally representative US sample. Journal of Behavioral Medicine, 2014 37(5): 977–987. [PubMed: 24072430]

34. Kudadjie-Gyamfi E, Consedine N, Magai C, Gillespie M, and Pierre-Louis J, Breast self-examination practices among women from six ethnic groups and the influence of cancer worry. Breast Cancer Research and Treatment, 2005 92(1): 35–45. [PubMed: 15980989]

35. Weil J, Multicultural education and genetic counseling. Clinical Genetics, 2001 59(3): 143–149. [PubMed: 11260220]

36. Bentley AR, Callier S, and Rotimi CN, Diversity and inclusion in genomic research: why the uneven progress? Journal of Community Genetics, 2017 8(4): 255–266. [PubMed: 28770442]

37. Hindorff LA, Bonham VL, Brody LC, Ginoza ME, Hutter CM, Manolio TA, and Green ED, Prioritizing diversity in human genomics research. Nature Reviews Genetics, 2018 19(3): 175–185.

38. Hay JL, Berwick M, Zielaskowski K, White KA, Rodríguez VM, Robers E, Guest DD, Sussman A, Talamantes Y, and Schwartz MR, Implementing an internet-delivered skin cancer genetic testing intervention to improve sun protection behavior in a diverse population: protocol for a randomized controlled trial. JMIR Research Protocols, 2017 6(4): e52–e82. [PubMed: 28442450]

39. Baty BJ, Kinney AY, and Ellis SM, Developing culturally sensitive cancer genetics communication aids for African Americans. American Journal of Medical Genetics Part A, 2003 118(2): 146–155.

40. Lucas T, Manning M, Hayman LW, and Blessman J, Targeting and tailoring message-framing: the moderating effect of racial identity on receptivity to colorectal cancer screening among African–Americans. Journal of Behavioral Medicine, 2018 41(6): 747–756. [PubMed: 29882172]
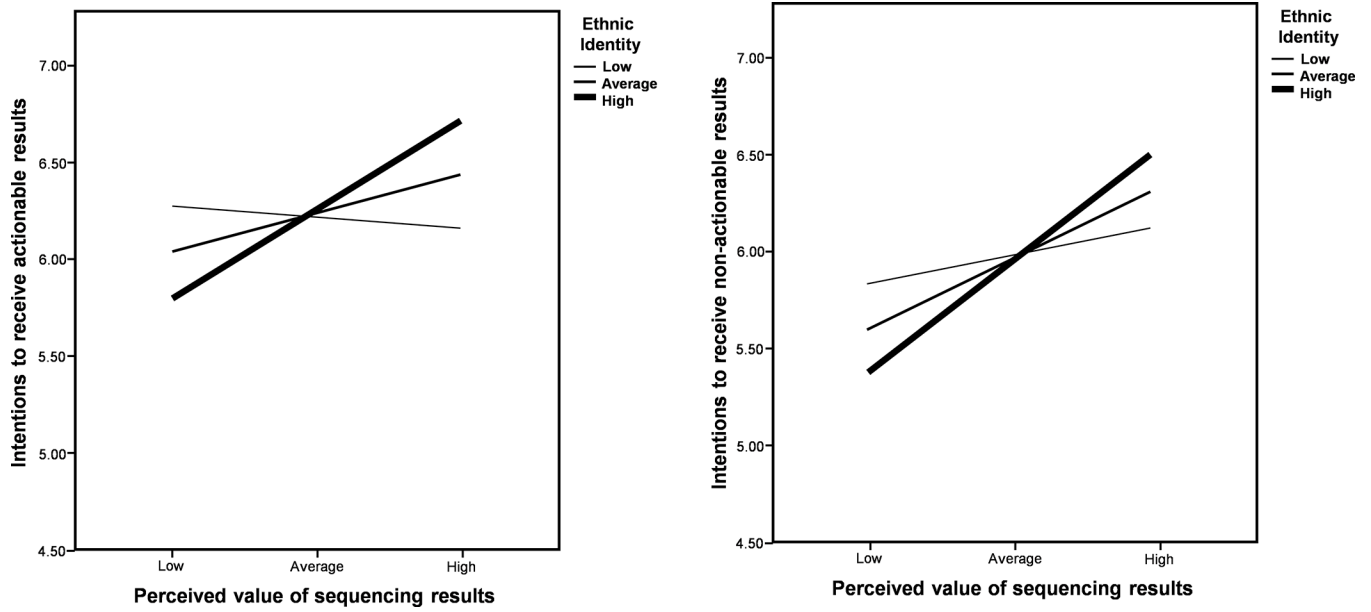
Figure 1.
Simple slopes (regression of the outcome on the predictor at a specific value of the moderator) of perceived value of genomic results predicting intentions to receive actionable or non-actionable disease risk results for 1 *SD* below the mean of ethnic identity (low), the mean of ethnic identity (average), and 1 *SD* above the mean of ethnic identity (high). The predictor variable is displayed as low (1 *SD* below the mean), average (the mean) and high (1 *SD* above the mean).

Figure 2.
Simple slopes (regression of the outcome on the predictor at a specific value of the moderator) of expected benefits from genomic research participation predicting intentions to receive actionable or non-actionable disease risk results for 1 *SD* below the mean of ethnic identity (low), the mean of ethnic identity (average), and 1 *SD* above the mean of ethnic identity (high). The predictor variable is displayed as low (1 *SD* below the mean), average (the mean) and high (1 *SD* above the mean).
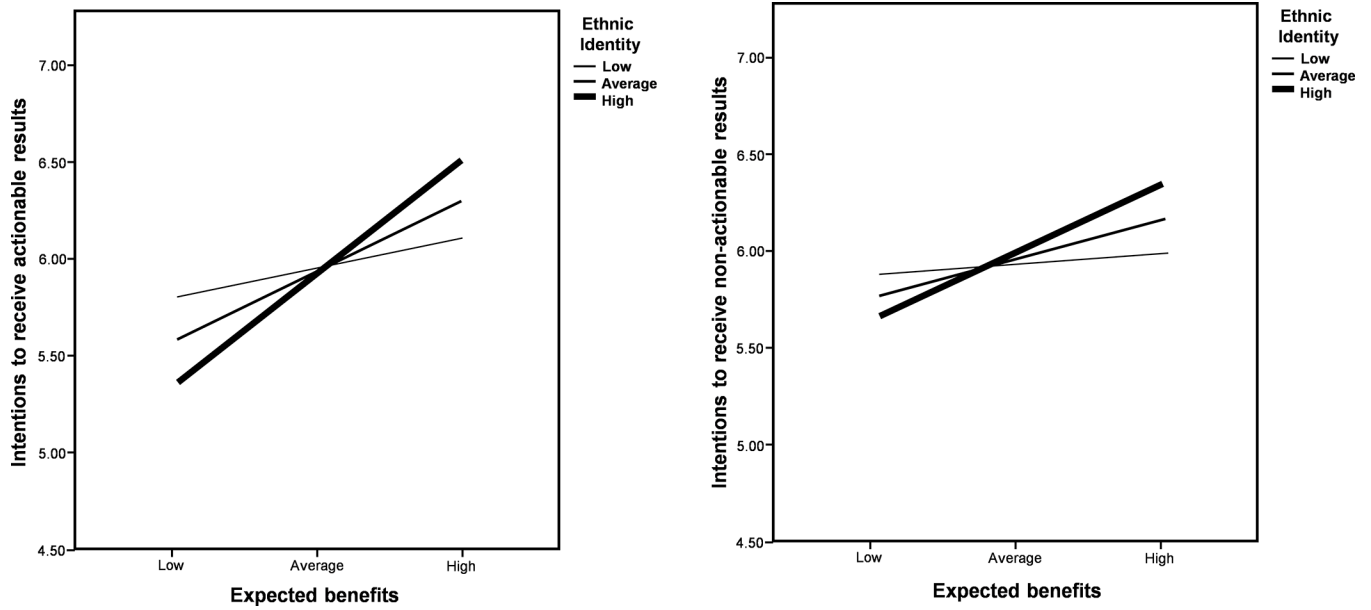
Figure 3.
Simple slopes (regression of the outcome on the predictor at a specific value of the moderator) of expected harms from genomic research participation predicting intentions to receive actionable or non-actionable disease risk results for 1 *SD* below the mean of ethnic identity (low), the mean of ethnic identity (average), and 1 *SD* above the mean of ethnic identity(high). The predictor variable is displayed as low (1 *SD* below the mean), average (the mean) and high (1 *SD* above the mean).
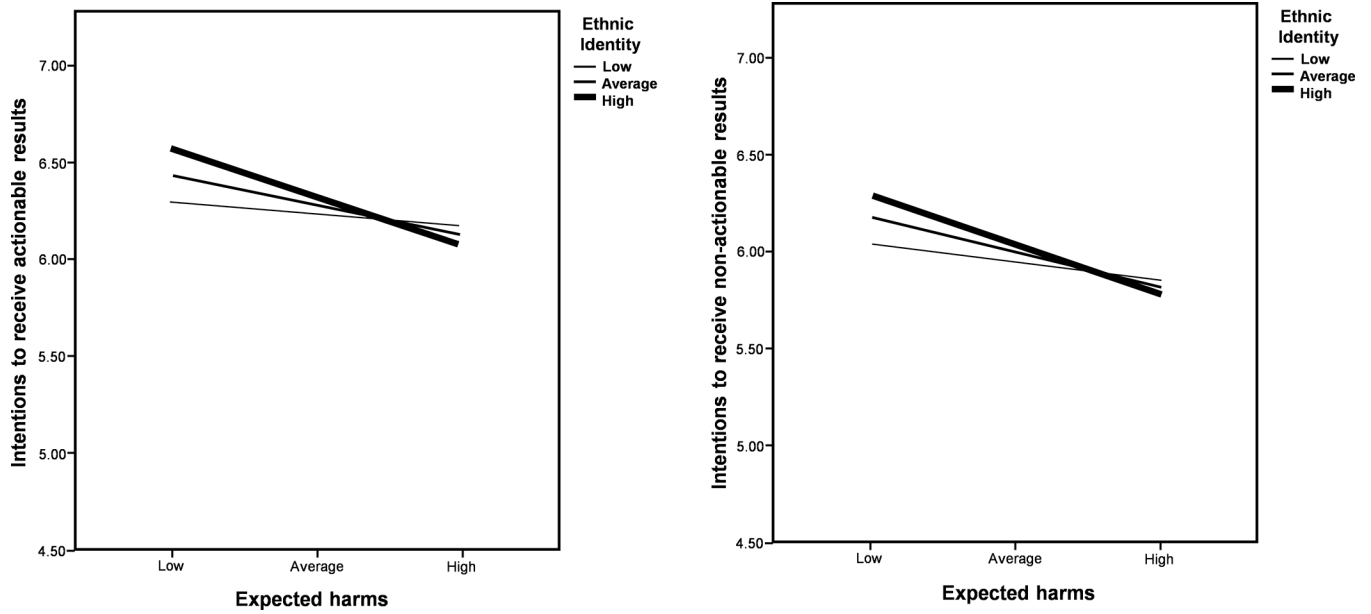
Table 1.

Participant characteristics and descriptive statistics for variables tested

Variable	Survey Respondents (n = 408)		
	n	%	
Female	306	75.0	
College Graduate or Beyond	267	65.4	
Annual Household Income >$100,000	151	37.0	
Hispanic or Latino	4	1.0	
			Mean (SD)
Age at survey completion			57.5 years (6.2)

	Possible range	Actual range	
MEIM total	1–4	1.2–4	3.29 (0.53)
Intentions: actionable	1–7	1–7	6.21 (1.50)
Intentions: non-actionable	1–7	1–7	5.93 (1.60)
Perceived value	1–5	1–5	4.31 (0.74)
Affective risk perception	1–7	1–7	2.26 (1.23)
Expected benefits	1–7	1–7	5.54 (1.15)
Expected harms	1–7	1–7	2.41 (1.34)

Table 2.

Correlation matrix showing Pearson coefficients for relationship between individual measures

		MEIM	Intentions: actionable[c]	Intentions: non-actionable[c]	Perceived value[c]	Expect benefits[c]	Expect harms[c]	Affective risk perception
MEIM[a]	r(bivariate), p	1	0.145, 0.006 *	0.126, 0.02	0.152, 0.003 *	0.181, 0.0005 *	−0.142, 0.007 *	0.097, 0.06
	r(multivariate)[b], p		0.08, 0.2	0.111, 0.05	0.204, 0.0003 *	0.177, 0.002 *	−0.111, 0.05	0.076, 0.2
Intentions: actionable	r(bivariate), p		1	0.784, 0.0001 *	0.223, 0.0001 *	0.274, 0.0001 *	−0.236, 0.0001 *	0.038, 0.5
	r(multivariate)[b], p			0.775, 0.0001 *	0.238, 0.0001 *	0.239, 0.0001 *	−0.269, 0.0001 *	0.030, 0.6
Intentions: non-actionable	r(bivariate), p			1	0.275, 0.0001 *	0.275, 0.0001 *	−0.226, 0.0001 *	0.006, 0.9
	r(multivariate)[b], p				0.289, 0.0001 *	0.239, 0.0001 *	−0.265, 0.0001 *	0.035, 0.5
Perceived value	r(bivariate), p				1	0.486, 0.0001 *	−0.140, 0.005 *	−0.065, 0.2
	r(multivariate)[b], p					0.495, 0.0001 *	−0.130, 0.02	−0.012, 0.8
Expect benefits	r(bivariate), p					1	−0.305, 0.0001 *	−0.029, 0.6
	r(multivariate)[b], p						−0.278, 0.0001 *	0.043, 0.5
Expect harms	r(bivariate), p						1	0.201, 0.0001
	r(multivariate)[b], p							0.143, 0.01
Affective risk perception	r(bivariate), p							1
	r(multivariate)[b], p							

[a]MEIM: multigroup ethnic identity measure

[b]Multivariate controlling for demographics correlated with MEIM in bivariate analyses (age and education)

[c]Spearman correlation for data that are not normally distributed used for these variables

*Correlation is significant after applying the Holm-Bonferroni correction for multiple comparisons