ARTICLE
Increasing access to individualized medicine: a matched-cohort study examining Latino participant experiences of genomic screening

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PURPOSE: Multiple efforts are underway to increase the inclusion of racial minority participants in genomic research and new forms of individualized medicine. These efforts should include studies that characterize how individuals from minority communities experience genomic medicine in diverse health-care settings and how they integrate genetic knowledge into their understandings of health-care needs.

METHODS: As part of a large, multisite genomic sequencing study, we surveyed individuals to assess their decision to pursue genomic risk evaluation. Participants included Latino patients recruited at Mountain Park Health Center, a Federally Qualified Health Center in Phoenix, Arizona, and non-Latino patients recruited at a large academic medical center (Mayo Clinic in Rochester, MN). Both groups agreed to receive individualized genomic risk assessments.

RESULTS: Comparisons between cohorts showed that Latino respondents had lower levels of decisional conflict about pursuing genomic screening but generally scored lower on genetic knowledge. Latino respondents were also more likely to have concerns about the misuse of genomic information, despite both groups having similar views about the value of genomic risk evaluation.

CONCLUSION: Our results highlight the importance of evaluating sociocultural factors that influence minority patient engagement with genomic medicine in diverse health-care settings.

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INTRODUCTION
While genomic medicine has the potential to improve health-care outcomes for patients, it could also widen existing health disparities between different racial groups.1,2 Already, racial disparities in access,3–5 health service utilization,6 and diagnosis7,8 have been documented. Recognizing these very different possibilities, commentators have called for greater inclusion of racial minority populations in genomic research to enhance the utility of genomic findings and ensure the widest benefit for all.2,9–16 In response, genomic implementation studies have expanded to include more racial minority participants and efforts have been made to prioritize the inclusion of diverse populations in genomic medicine. Additionally, federal investments in genomic medicine, such as the All of Us Research Program,17 have made the inclusion of diverse populations a priority.

Despite these successes, however, we still have very limited familiarity with how individuals from minority racial or ethnic populations engage with translational genomic research or integrate genetic knowledge into their understandings of health-care needs. Of particular note is the limited body of published research describing the clinical support needs of racially diverse patients who receive genomic evaluation in health-care settings that are not academic medical centers or university hospitals.18–22 This lack of data on patient receptivity to genomic medicine—specifically within more diverse clinical contexts where significant numbers of minority patients receive their health care—will complicate efforts to prevent the health disparities that commitments to greater inclusiveness are intended to address.

To begin to address this gap, we surveyed Latino patients who receive care at a Federally Qualified Health Center (FQHC) in Phoenix, Arizona. In parallel, the survey was conducted in a more affluent, predominantly non-Latino population of patients who receive care at a large academic medical center. Both groups received the same genomic risk evaluation as part of a multisite genomic research initiative, allowing us to compare their experiences directly. The aim of these parallel survey efforts was to characterize how the beliefs and experiences of patients from a less affluent, predominantly Spanish-speaking Latino community compare with the experiences of other populations that have been more fully characterized in prior studies examining the psychosocial impact of genomic medicine. Our results highlight several important challenges and patient-support needs that should be considered in promoting increased access to genomic medicine in diverse communities.

MATERIALS AND METHODS
Setting and participants
We surveyed individuals enrolled in the Return of Actionable Variants Empirical (RAVE) study, a genomic sequencing study at Mayo Clinic in Rochester, Minnesota and Mountain Park Health Center (MPHC) in Phoenix, Arizona. A full description of the RAVE study, including its aims and recruitment procedures, has been published previously.23,24 Differences

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between participant populations and the clinical care available at these sites provided a natural context in which to conduct a comparative analysis of participant experiences of genomic risk evaluation.

Inclusion criteria for the genomic sequencing study (at both sites) were ≥18 years of age and having either colon polyps and/or hyperlipidemia. Mayo Clinic participants were recruited from two biorepositories—the Mayo Clinic Biobank and the Mayo Clinic Vasculitis Biorepository. Since participants had previously donated biological materials as part of their enrollment in a biorepository, blood samples were available at the time participants were approached to participate in the study. Sequencing involved evaluation of 68 medically actionable genes, including 59 genes identified by the American College of Medical Genetics and Genomics and 14 additional single-nucleotide variants. Participants who agreed to participate in the study were informed that they would be notified about their individual results when those results became available and that the results would be placed in their electronic health record.

Mayo Clinic participants were invited to participate by way of a mailed packet that contained an invitation letter, a study brochure, a “frequently asked questions” document, a consent form, and a self-addressed, stamped return envelope to facilitate completion and return of the informed consent form. MPHIC participants were recruited from the Sangre Por Salud biobank, and were sent a study invitation letter, followed by a phone call to set up an in-person educational session to discuss study participation. MPHIC participants who attended the in-person educational session viewed an educational video describing genomic sequencing and reviewed the consent materials with a research staff member. Following the educational session, MPHIC participants interested in participating in the study signed a written consent form. MPHC participants interested in participating in the study attended an in-person educational session. The survey was completed during an in-person enrollment session. The survey was completed by research staff from the Survey Research Center at Mayo Clinic. A bilingual research coordinator (I.C.) was available to answer participant questions about the survey and assist lower literacy participants in completing the survey, as needed.

Completed surveys from both cohorts were double entered and verified by research staff from the Mayo Clinic Survey Research Center at Mayo Clinic. A research team member (J.E.P.) reviewed paper copies of all surveys containing anomalies in survey responses.

Data analysis

Descriptive statistics were produced for both cohorts, including frequency distributions for categorical variables and means and standard deviations for continuous variables. Decisional conflict scores and proportions of correct responses to knowledge about genomic sequencing items were calculated. Summary statistics were calculated using JMP Pro 14 (2018 SAS Institute Inc.).

To compare perspectives on genomic screening in the MPHIC cohort (which are not as well characterized) to the Mayo Clinic population (which has been studied more extensively), we created a simulated case–control cohort by matching MPHIC participants 1-to-1 with participants in the Mayo Clinic cohort on as many variables as possible. Several candidate matching models were generated, which varied from each other with respect to (1) which variables they employed imputation for missing data, and (2) the number of variables included in the matching model. Imputation enabled us to retain a few cases with data missing from the matching variables in each cohort. Our goal was to retain as many cases from the smaller MPHIC cohort as possible, while minimizing standardized differences between cases and controls. To achieve this goal, the final model included an absolute match on sex and an approximate match on age (±5 years) and employment status, and that the results would be placed in their electronic health record.
Table 1. Demographic characteristics of two cohorts of participants who received genomic risk evaluation; n = 802.

|                        | Mayo Clinic N (%) | Mountain Park Health Center N (%) | p value |
|------------------------|-------------------|----------------------------------|---------|
| Sex                    |                   |                                  | 0.95b   |
| Male                   | 104 (26.5)        | 104 (26.3)                       |         |
| Female                 | 288 (73.5)        | 291 (73.7)                       |         |
| Ethnicity              |                   |                                  | <0.01b  |
| Latino                 | 2 (0.5)           | 383 (99.2)                       |         |
| Not Latino             | 390 (99.5)        | 3 (0.8)                          |         |
| Survey language        |                   |                                  | <0.01b  |
| English                | 401 (100)         | 73 (18.2)                        |         |
| Spanish                | 0 (0)             | 328 (81.8)                       |         |
| Marital status         |                   |                                  | <0.01b  |
| Married/partnered      | 336 (85.7)        | 276 (70.6)                       |         |
| Not married/partnered  | 56 (14.3)         | 115 (29.4)                       |         |
| Age (years)            |                   |                                  | 0.57c   |
| Mean (SD)              | 48.6 (10.2)       | 48.2 (10.5)                      |         |
| Range                  | 26–71             | 23–73                            |         |
| Insurance coverage     |                   |                                  |         |
| Employer-based         | 343 (85.5)        | 35 (8.7)                         | <0.01b  |
| Privately purchased    | 13 (3.2)          | 7 (1.7)                          | 0.17b   |
| Government program     | 51 (12.7)         | 138 (34.4)                       | <0.01b  |
| No insurance           | 4 (1.0)           | 203 (50.6)                       | <0.01b  |
| Employment             |                   |                                  | <0.01b  |
| Full time              | 270 (67.3)        | 94 (23.4)                        |         |
| Part time              | 52 (13.0)         | 58 (14.5)                        |         |
| Not currently employed | 79 (19.7)         | 249 (62.1)                       |         |
| Health literacy        |                   |                                  | <0.01b  |
| Adequate               | 380 (95.5)        | 281 (75.3)                       |         |
| Inadequate             | 18 (4.5)          | 92 (24.7)                        |         |
| Education              |                   |                                  | <0.01b  |
| Less than high school graduate | 1 (0.3) | 245 (63.1) |         |
| Grade 12 or GED        | 32 (8.0)          | 78 (20.1)                        |         |
| College 1–3 years      | 144 (36.1)        | 44 (11.3)                        |         |
| College 4 years or more| 134 (33.6)        | 15 (3.9)                         |         |
| Graduate school        | 88 (22.1)         | 6 (1.5)                          | <0.01b  |
| Physical exam within last two years | 301 (75.1) | 338 (84.3) |         |
| Plan to share results with a physician | 178 (44.6) | 330 (84.8) | <0.01b  |
| Plan to share results with a family member | 329 (82.5) | 282 (73.1) | <0.01b  |

*a*Includes divorced, separated, widowed, or single.  
*b*Chi-square.  
*c*Two-sample t-test.

Individuals in the decisional conflict scale across cohorts. On all but four items, the MPHC cohort was at statistically higher odds of indicating agreement. For example, MPHC participants were more likely to indicate agreement with the statement “I am clear about which benefits of participating in the study matter most to me” than their Mayo Clinic counterparts (odds ratio [OR] 16.00, 95% confidence interval [CI]: 5.16–80.31, p < 0.0001). Similarly, MPHC participants were more likely to agree that they “knew the benefits of participating” (OR: 15.00, 95% CI: 3.81–129.54, p < 0.0001) and “knew the risks of participating” (OR: 13.67, 95% CI: 4.36–68.99, p < 0.0001). All 16 items from the decisional conflict scale are presented in Table 2 in descending order of comparative odds of agreement by MPHC survey respondents.

Paired comparisons of cohort responses to anticipated psychosocial outcomes are included in Table 3. For each item examining a favorable outcome of participating in the study, MPHC participants were more likely than Mayo Clinic participants to indicate endorsement. For example, MPHC participants were much more likely to endorse the notion that “favorable results will bring me peace of mind” when compared with the Mayo Clinic cohort (OR: 4.2, 95% CI: 2.53–7.36, p < 0.0001). MPHC participants also were more likely to believe that their results would give them more control over their health (OR: 3.70, 95% CI: 2.50–5.61, p < 0.0001). Finally, MPHC participants were more likely to value a genomic result of any kind, including learning about a genetic predisposition to disease not associated with the study’s phenotypic inclusion criteria (hyperlipidemia or colon polyps) (OR: 2.29, 95% CI: 1.27–4.32, p < 0.05).

Paired comparisons of cohort responses to items examining psychosocial outcomes related to unfavorable outcomes of receiving genomic screening results are also included in Table 3. MPHC participants were more likely to express concern about the effect of the results on their family relationships (OR: 9.93, 95% CI: 5.83–18.19, p < 0.0001) and more likely to believe that a positive genomic screen result would cause them to worry about their health (OR: 7.92, 95% CI: 5.16–12.66, p < 0.0001). MPHC participants also were more likely to be concerned about discrimination (OR: 6.44, 95% CI: 4.21–10.25, p < 0.0001) and confidentiality than their Mayo Clinic counterparts (OR: 2.46, 95% CI: 1.80–3.39, p < 0.0001). Additionally, MPHC participants were more likely to expect a pathogenic genomic result and more likely to express insecurity about their ability to cope with learning they were at increased genetic risk of disease.

Knowledge of genomic sequencing scores were calculated as a proportion of correct responses (0 to 1). The mean knowledge score for the Mayo Clinic cohort was 0.76 (SD = 0.20, median = 0.82). Knowledge scores for the MPHC cohort were lower, with a mean of 0.55 (SD = 0.24, median = 0.55, p < 0.0001; see Supplemental Fig. 2). Table 4 compares the cohorts on individual items in the knowledge of genomic sequencing measure. While the MPHC cohort was more likely to provide an incorrect answer to any individual item in the knowledge measure, when compared with the Mayo Clinic cohort, four items stood out with the highest comparative likelihood of an incorrect response from the MPHC cohort. The first item stated, “once a variant in a gene that affects a person’s risk of a disease is found, that disease can always be prevented or cured.” MPHC participants were at 12.3 times higher odds of providing an incorrect or uncertain response (i.e., True or Don’t Know; 95% CI: 7.62–21.20, p < 0.0001). Similarly, MPHC participants were more likely to respond incorrectly (i.e., False or Don’t Know) to the following statement: “Even if a person has a family member with a genetic result of any kind, including learning about a genetic predisposition to disease not associated with the study’s phenotypic inclusion criteria (hyperlipidemia or colon polyps)” (OR: 9.00, 95% CI: 5.06–17.41, p < 0.0001). MPHC participants also were more likely to answer incorrectly (i.e., True or Don’t Know) to the item, “Scientists know how all variants of genes will affect a person’s chances of developing diseases.”
psychosocial analysis of a minority population with a FQHC. In this context, we also conducted a comparative participation in a genomic sequencing study in the context of a academic medical center. Kaphingst and colleagues conducted a hypothetical vignette-based survey in urban community health centers and assessed minority perspectives about genomic medicine in care settings that are not academic medical centers. While our data have limitations, which are discussed below, at least three observations can be made that may inform future efforts to increase the inclusiveness of genomic medicine and research.

To date, however, few (if any) studies have examined the experiences and decision making processes of Latino patients who elect to receive genomic evaluation of disease risks (i.e., a health-care provider can tell a person their exact chance of developing a disease based on the results from genome sequencing) or other participants when they enrolled enhanced their feelings of agreement (OR: 8.83, 95% CI: 5.78–14.09, p < 0.0001). Fourthly, MPhC participants were more likely to answer incorrectly (i.e., True or Don’t Know) the item, “A health-care provider can tell a person what is important to them (the benefits or the risks)” (OR: 7.64, 95% CI: 5.02–11.51, p < 0.0001). Odds ratios were smaller for the remaining knowledge measure items (see Table 4).

**DISCUSSION**

Our study examined psychosocial outcomes associated with participation in a genomics screening study in the context of a FQHC. In this context, we also conducted a comparative psychosocial analysis of a minority population with a “matched control” cohort of participants receiving the same test in the context of an academic medical center.

Very few studies, to date, have focused on minority community perspectives on genomic medicine in care settings that are not academic medical centers. Kaphingst and colleagues conducted a hypothetical vignette-based survey in urban community health centers and assessed minority perspectives about genomic research. As in our study, Kaphingst and colleagues focused on the experiences and decision making processes of racial minority populations not connected to an academic medical center. Sanderson and colleagues interviewed 205 individuals at an outpatient clinic in an inner-city hospital (29% of whom were Latino) to assess willingness to participate in a hypothetical genomic research study. Additionally, Hoskins and colleagues conducted a study examining the feasibility of increasing recommended referrals for genetic counseling for breast cancer within a FQHC, and Komenaka and colleagues assessed the participation of low-income women (70% of whom where Latino) in BRCA1/2 testing within the context of a safety net institution. Finally, Rana and colleagues examined the comparative outcomes of cancer genetics consultations in an academic medical center and an FQHC and found lower uptake of genetic testing among patients from the FQHC. These studies represent rigorous efforts to reach outside the environment of the academic medical center and characterize minority perspectives on genomic research.

| Beliefs about the decision to pursue genomic screening | Mayo Clinic N (%) | MPhC N (%) | Comparative odds of MPhC indicating agreement | 95% confidence interval (CI) |
|-------------------------------------------------------|------------------|------------|--------------------------------------------|-----------------------------|
| I am clear about which benefits of participating in the study matter most to me | 348 (87) | 371 (99) | 16.00<sup>d</sup> | 5.16–80.31 |
| I know the benefits of participating in the study | 368 (92) | 375 (99) | 15.00<sup>d</sup> | 3.81–129.54 |
| I know the risks of participating in the study | 353 (88) | 364 (98) | 13.67<sup>d</sup> | 4.36–68.99 |
| I am clear about which risks matter most to me | 340 (85) | 368 (98) | 11.00<sup>d</sup> | 4.44–35.21 |
| I am clear that participating in the study was the best choice for me | 347 (87) | 377 (99) | 10.20<sup>d</sup> | 4.10–32.75 |
| My decision reflects what is important to me | 370 (93) | 383 (98) | 5.80<sup>d</sup> | 2.22–19.19 |
| I feel sure about my choice | 351 (88) | 358 (97) | 4.50<sup>d</sup> | 2.24–10.01 |
| I feel I have made an informed choice | 376 (94) | 378 (98) | 4.00<sup>c</sup> | 1.59–11.96 |
| I had enough support from others when I made my choice | 383 (96) | 378 (99) | 3.40<sup>c</sup> | 1.20–11.79 |
| The decision was easy for me to make | 354 (89) | 369 (96) | 3.07<sup>c</sup> | 1.65–6.08 |
| I am satisfied with my decision | 389 (97) | 378 (99) | 2.20 | 0.70–8.08 |
| I had enough advice when I made my choice | 292 (73) | 289 (83) | 1.82<sup>c</sup> | 1.22–2.76 |
| I chose without pressure from others | 390 (98) | 378 (98) | 1.13 | 0.39–3.35 |
| I know I had the option to participate or not participate in the study | 396 (99) | 373 (99) | 1.00 | 0.13–7.47 |
| I expect to stick with my decision | 393 (98) | 349 (94) | 0.29<sup>c</sup> | 0.11–0.70 |

<sup>a</sup>Items are from the decisional conflict scale, N (%) of respondents indicating Agree or Strongly Agree.

<sup>b</sup>Mountain Park Health Center.

<sup>c</sup>p < 0.05.

<sup>d</sup>p < 0.0001.
This conclusion assumes that the decision to participate in a genomic sequencing study would have otherwise been a difficult one for some participants in the MPHC cohort due to a historic underrepresentation in research and known literacy and health literacy challenges in Latino populations. We were reassured by the low levels of decisional conflict measured in the MPHC cohort, and we attributed the decisional clarity we observed to the in-person, culturally competent engagement that participants received at the time of study enrollment. Future research could explore in greater depth the sources and meaning of decisional conflict in Latino communities, including the potential influence of knowledge, health literacy and English-language proficiency on decisional conflict. Future research could also explore potential implications of elevated decisional conflict for the pursuit of genomic risk evaluation.

Second, our data suggest that Latino participants from a FQHC in the Phoenix area may have stronger opinions about the potential impact of genomic screening compared with non-Latino participants who receive care at an academic medical center in the Upper Midwest. For example, MPHC participants were more likely than Mayo Clinic participants to endorse the potential for favorable psychosocial outcomes from participating in a genomic screening study, such as greater peace of mind as a result of receiving a negative result, and greater control over their health. More participants at MPHC exhibited appreciation for genetic information of any kind, and more intended to share their screening results with a physician. Conversely, MPHC participants were also more likely to have significant reservations about genomic screening and its potential to produce negative outcomes. For example, MPHC participants were significantly more likely to express concerns about confidentiality, discrimination, and the potential for negative effects on family members. MPHC participants also were more likely to anticipate unfavorable test results and were more likely to express personal insecurities about their ability to cope with learning they have a greater risk of disease due to their genetics. These more extreme views of both the potential positive and negative outcomes of genomic screening may be the result of limited familiarity with new forms of genomic medicine. Our findings suggest that some of the traditional ethical considerations in genomic medicine and research may require additional evaluation as access to genomic medicine is expanded to include historically underrepresented populations in genetic research.

Third, our results highlight several potential priority areas for future educational interventions. The MPHC cohort scored lower than the Mayo Clinic cohort on several items related to knowledge about genomic sequencing. The top four questions most likely to be answered incorrectly by the MPHC cohort had to do with beliefs about penetrance (“Scientists know how all variants of genes will affect the risk of a disease, they may not develop that effect prevention or cure (Even if a person has a variant in a gene that affects their risk of a disease, they may not develop that disease”), beliefs about the capability of the health system to effect prevention or cure (“Once a variant in a gene that affects a person’s risk of a disease is found, that disease can always be prevented or cured”), and beliefs about the role of health professionals (physicians and scientists) in utilizing genomic information (“Scientists know how all variants of genes will affect a person’s chances of developing diseases” and “A health-care provider can tell a person their exact chance of developing a

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Table 3. Comparison of anticipated psychosocial outcomes resulting from genomic risk evaluation.

| Comparison of anticipated psychosocial outcomes | Mayo Clinic N (%) | MPHC N (%) | Comparative odds of MPHC indicating agreement | 95% confidence interval (CI) |
|-----------------------------------------------|-------------------|------------|---------------------------------------------|-------------------------------|
| Favorable psychosocial outcomes               |                   |            |                                             |                              |
| Results indicating no genetic disease risk will bring me peace of mind | 313 (78)          | 363 (94)  | 4.21<sup>a</sup>                            | 2.53–7.36                    |
| Results will give me more control over my health | 256 (64)          | 329 (87)  | 3.70<sup>a</sup>                            | 2.50–5.61                    |
| Results indicating no increased genetic risk for disease are valuable to me | 298 (75)          | 331 (90)  | 3.33<sup>a</sup>                            | 2.09–5.50                    |
| Results indicating elevated risk for heart disease or colorectal cancer are valuable to me | 356 (89)          | 344 (93)  | 1.86<sup>a</sup>                            | 1.07–3.32                    |
| Results indicating I have some other disease risk are valuable to me | 354 (89)          | 346 (95)  | 2.29<sup>a</sup>                            | 1.27–4.32                    |
| Unfavorable psychosocial outcomes              |                   |            |                                             |                              |
| I am concerned about detrimental effects of results on family relationships | 23 (6)            | 158 (41)  | 9.93<sup>a</sup>                            | 5.83–18.19                   |
| Results indicating increase risk of disease will cause me to worry | 154 (39)          | 313 (82)  | 7.92<sup>a</sup>                            | 5.16–12.66                   |
| I am concerned that I will feel labeled or singled out if I tell others that I have elevated genetic risk for disease | 57 (14)           | 191 (49)  | 6.44<sup>a</sup>                            | 4.21–10.25                   |
| I am concerned that my results may not stay confidential | 137 (34)          | 213 (56)  | 2.46<sup>a</sup>                            | 1.80–3.39                    |
| I am not completely confident about coping with a positive test result | 250 (63)          | 283 (73)  | 1.57<sup>a</sup>                            | 1.15–2.15                    |
| I am expecting a genomic result indicating increase risk of disease | 259 (65)          | 279 (74)  | 1.53<sup>a</sup>                            | 1.11–2.12                    |

<sup>a</sup>Mountain Park Health Center.
<sup>b</sup>N (%) indicating Agree or Strongly Agree vs. Neither Agree nor Disagree, Disagree, or Strongly Disagree.
<sup>c</sup>N (%) indicating Extremely Valuable or Quite Valuable vs. Slightly Valuable or Not At All Valuable.
<sup>d</sup>N (%) indicating Very Concerned or Somewhat Concerned vs. Slightly Concerned or Not At All Concerned.
<sup>e</sup>N (%) indicating Likely or Very Likely vs. Neither Likely nor Unlikely, Unlikely, or Very Unlikely.
<sup>f</sup><sup>p</sup> < 0.05.
<sup>g</sup><sup>p</sup> < 0.0001.
Once a variant in a gene that affects a person’s risk of a disease is found, that disease can always be prevented or cured 331 (84) 115 (30) 12.33\(^c\) 7.62–21.20

Even if a person has a variant in a gene that affects their risk of a disease, they may not develop that disease 359 (92) 245 (65) 9.00\(^c\) 5.06–17.41

Scientists know how all variants of genes will affect a person’s chances of developing diseases 316 (81) 111 (29) 8.83\(^c\) 5.78–14.09

A health-care provider can tell a person their exact chance of developing a disease based on the results from genome sequencing 315 (80) 119 (31) 7.64\(^c\) 5.02–11.51

Genome sequencing may find variants in a person’s genes that they can pass on to their children 369 (94) 330 (86) 2.58\(^b\) 1.49–4.64

Genome sequencing may give a person information about their chances of developing several different diseases 368 (94) 316 (84) 2.50\(^b\) 1.50–4.31

A person’s health habits, like diet and exercise, can affect whether or not their genes cause diseases 234 (60) 158 (42) 2.06\(^c\) 1.53–2.80

Genome sequencing may find variants in a person’s genes that may determine how they respond to certain medicines 242 (62) 176 (47) 1.74\(^b\) 1.29–2.37

Genome sequencing may find variants in a person’s genes that will increase their chance of developing a disease in their lifetime 337 (86) 294 (79) 1.67\(^b\) 1.12–2.50

Genome sequencing is a routine test that most people can have through their physician’s office 234 (60) 184 (49) 1.52\(^b\) 1.12–2.07

Genome sequencing may find variants in a person’s genes that will decrease their chance of developing a disease in their lifetime 194 (49) 173 (48) 1.06 0.80–1.42

\(^a\)Items are from the knowledge about genomic sequencing scale, N (%) correct responses.

\(^b\)\(p < 0.05\).

\(^c\)\(p < 0.0001\).

**Table 4.** Comparative performance on knowledge about genomic sequencing items.

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In our study, Mayo Clinic participants in our study are not fully representative of the diversity of patients who receive care at academic medical centers in the United States. As described elsewhere, participants in the MPHC cohort were difficult to recruit, in part, due to factors such as restrictive work schedules, transportation limitations, changing mailing addresses, and lower literacy. A majority of our MPHC cohort was female, had adequate health literacy, and reported having had a physical exam within the last two years. These considerations suggest that the MPHC cohort may be limited in its representativeness of the regional Latino community in Phoenix, as well as other Latino communities nationwide. Future research into the experiences of Latino participants receiving genomic evaluation at Federally Qualified Health Centers should seek to further characterize the heterogeneity in both regional and national Latino populations who receive care in those settings.

Secondly, because our survey was fielded in English and Spanish, the comparison of survey item responses across cohorts may be limited by cultural and linguistic factors. We attempted to address this using a rigorous translation and back-translation process, with subsequent cognitive testing in native Spanish speakers from the population we surveyed. We did not do psychometric validation, however, to confirm the fidelity of our items across languages.

Finally, there are limitations in our method of cohort comparison. We were unable to match the cohorts on variables beyond sex and age. The cohorts differed significantly on several other levels (see Table 1). Furthermore, as described above, recruitment procedures for participants in the RAVE study differed between the two cohorts, with in-person decision support and education provided to MPHC participants as part of the
enrollment process. The additional support provided to the MPHC cohort may confound our analysis of perceived psychosocial outcomes, particularly results pertaining to decisional conflict, in which the MPHC cohort reported less decisional ambivalence overall than the Mayo Clinic cohort. Additionally, we were unable to examine the intersectional impact of ethnicity and race on psychosocial outcomes in our comparison.

Despite these limitations, our findings illuminate broad differences in the psychosocial impact of genomic screening on differentially advantaged populations. Comparative studies examining the psychosocial impacts of genomic medicine are uncommon but much needed as genomic medicine is extended to more diverse clinical contexts. While the specific differences we observed may not be confirmed in future studies, it is unlikely that the observed variation in psychosocial impact we observed would disappear altogether in other studies examining the impact of genomic medicine on racial and ethnic minorities that historically have not been adequately represented in genomic research.

Conclusion

As genomic medicine expands, continued engagement with racial and ethnic minority populations is critical to ensure that the needs of diverse communities are met in culturally sensitive ways. Our data suggest that bioethical concerns that have been studied extensively in more affluent majority populations will need to be re-evaluated in lower resource settings where racial and ethnic minorities often receive care. Our findings also suggest that differences in attitudes and beliefs about genomic medicine may be influenced by broader cultural norms that are themselves reflective of shared social, economic, political, and other experiences that shape Latino perspectives on health and health care. As a result, interventions that have been created in support of the genomic medicine on racial and ethnic minorities that would disappear altogether in other studies examining the psychosocial impact of genomic medicine on racial and ethnic minorities is critical to ensure that the needs of diverse communities are met in culturally sensitive ways.

Supplemental data

Supplemental data include two boxplot figures showing the distributions, medians, and interquartile ranges of the total Decisional Conflict Scale scores and the Knowledge About Genome Sequencing scale scores for both cohorts.

DATA AVAILABILITY

Survey data may be made available on a case by case basis by contacting the principal investigator of the study.

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COMPETING INTERESTS
The authors declare no competing interests.

ETHICS DECLARATION
This survey study was embedded in two parent genomic sequencing studies, each of which was reviewed and approved by the Mayo Clinic Institutional Review Board (#15–005013 and #16-004342). Written informed consent was obtained for all participants.

ADDITIONAL INFORMATION
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