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ORIGINAL ARTICLE

Patient Perspectives and Demographic Factors Influencing Non-Participation in a Large Genomics Study

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Abstract

Objectives: To describe reasons why patients declined to participate in the Tapestry whole exome sequencing study and examine demographic trends in responses.

Patients and Methods: The Tapestry study enrolled patients 18 years of age and over, beginning July 1, 2020, through May 31, 2024. This study includes 12,705 recruited subjects who declined to participate before February 14, 2022, but provided reasons for declination (RPs). RPs were selected from 5 discrete reasons for declination and had the opportunity to add a free-text comment. Comments were classified into 7 theme-based categories by the reviewers for analysis. Demographics of the subjects, including age, race, ethnicity, having a primary care provider, and rural–urban commuting area, were compared based on consent status and their reasons for declination.

Results: RPs had a mean age of 61 years, were 90.1% White, and were 57.4% female. The most common reasons for declination were concerns about storing genetic data in electronic health records, the complexity of the process, and discomfort with genetic research. Significant differences in reasons for declination were found by sex, age, race, ethnicity, primary care provider status, and rural–urban commuting area.

Conclusion: Our study highlights demographic and structural factors influencing genomic study non-participation. Distinct barriers were identified among active decliners, including privacy concerns, logistical issues, and mistrust. These findings emphasize the need for targeted education and provider engagement to support informed decision-making, reduce post-genomic sequencing regret, and promote equity in participation in large-scale personalized medicine initiatives.

Rapid scientific and methodological advances in genomics have contributed to the growth of personalized medicine, in which prevention, diagnosis, and treatment strategies may be tailored to individual characteristics.[1] Developments in genomic sequencing have deepened our understanding of the genetic and molecular basis of various diseases and also contributed to the rise of personalized medicine.[2] These advancements, paired with extensive growth of our knowledge in genomics, have led to a transition in medicine from a "one-size-fits-all" approach to personalized health care models.[3]

Large-scale genomic research depends on voluntary participation from individuals who choose to share biological samples, health records, and genomic data for research purposes.[4] Understanding the reasons individuals decline participation is essential to ensuring transparency, trust, and respect

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for autonomy, particularly as genomic initiatives increasingly intersect with clinical care. Research on large-scale biobanks has demonstrated that active refusal (ie, clearly declining an invitation) and passive nonresponse (ie, not replying at all) represent 2 distinct forms of non-participation, each linked to different underlying reasons. Active refusers often express concerns about privacy, while passive non-responders are more likely to report time limitations or logistical barriers.[5] Failing to differentiate between these groups may obscure important drivers of disengagement and limit the impact of recruitment strategies, particularly in large-scale genomic screening efforts.

As genomic research and screening initiatives expand, considerable attention has been directed toward understanding why some individuals and populations decline participation. A systematic review of public attitudes and participation revealed recurring reasons for refusal, including apprehensions about confidentiality and data privacy, distrust in medical care and governmental institutions, limited perceived personal benefit, concerns about possible repercussions for family members, and anxiety over retaining insurance coverage.[6]

These findings were reflected in additional studies that also cited reasons such as lack of time due to other responsibilities,[7] difficulty in understanding the provided information,[8] and limited accessibility. Personal beliefs or values that conflict with participation in research and/or genomic studies are also a concern that has been raised by refusing subjects.[9] Furthermore, research has revealed differences in willingness to participate based on racial or ethnic identity and other demographic characteristics.[8]

Although non-participation in genomic research is a valid choice within a voluntary framework, limited representation may compromise the generalizability of genomic findings across diverse populations. Broad representation in genomic research enables deeper insights into disease risk across populations, ultimately facilitating more precise pharmacological treatments and interventions.[10,11]

Participation of minority groups in genomic research has remained persistently limited over time.[12,13] This has shown to be especially true of African Americans, Hispanic/Latinos, Native American/American Indians, and rural communities.[9,13-15] According to a prior study, 92% of participants in a US genomic-wide association studies up until 2009 were White, followed by 3% African Americans.[10]

Individuals living in rural areas often encounter significant obstacles to obtaining primary and genomic health care, including geographic isolation, a lower density of practicing primary care providers (PCPs), and insufficient access to specialist referral systems. Uneven distribution of the genetics workforce and limited availability of trained genetic professionals further exacerbate these service gaps, particularly in rural and medically underserved communities.[14,16]

The Mayo Clinic Tapestry study was launched in 2020 and has since then accumulated 98,005 currently consented participants with Exome+ assay data available. In collaboration with Helix Inc., Mayo Clinic has created a library of sequenced data from consented participants to advance research and improve patient care. As part of Tapestry, whole exome sequencing was performed to identify clinically actionable variants in 11 Center for Disease Control Tier 1 genes associated with 3 conditions: hereditary breast and ovarian cancer syndrome, Lynch syndrome, and familial hypercholesterolemia.[17] These results were returned to participants and have been made available to Mayo Clinic provider to access the benefits of Exome+ assay sequencing, including the impact on health-related outcomes, health care utilization, and physician application. Genomic and phenotypic data are also stored for future research analysis.

Informed on the previously researched trends and challenges of genomic studies, Mayo Clinic researchers sought to (1) quantify participation patterns in the Tapestry study by categorizing individuals into consenters, decliners who provided reason(s) for declination, and decliners who did not provide reasons; (2) characterize structured and self-reported reasons among responses provided (RPs); and (3) evaluate how these reasons and their themes varied according to demographic and clinical characteristics, including age, biological sex, race, ethnicity,

rurality, and access to a PCP, using the Mayo Clinic Tapestry study.

PATIENTS AND METHODS

Study Population

This study includes all individuals who were invited to the Tapestry study as of February 14, 2022. The Tapestry invitation email template is available in the supplemental material. Patient age, sex, race, and ZIP code of residence were gathered from our institution's registration database. Subjects invited for participation were initially classified into 2 groups: (1) those who consented and (2) those who declined participation, either actively by responding no to the invitation or passively by failing to reply to the invitation. Subjects who actively declined participation were asked to complete a brief questionnaire that collected information on reasons for declining. Those who provided reasons were classified into the decline, RP group, while those who did not provide reasons and those who passively declined were classified into the declined, response not provided (RNP) group. For RPs, the following 5 structured reasons were included on the questionnaire using a check all that apply format: (1) "I am not interested in knowing my genetic risk for these diseases"; (2) "I do not want genetic results in my electronic health record"; (3) "I am concerned about the impact of genetic results on my ability to get life and/or long-term care insurance"; (4) "I am uncomfortable with genetic research"; and (5) "The process is too complicated." RPs were also allowed to check an "Other" box and provide free-text responses for additional reasons for declining. These qualitative responses were categorized into structured themes by 3 reviewers (A.D.C., S.M.B., and D.J.B.). Subjects providing a response indicative of a given theme were classified as "yes" for that theme and those not providing such a response were classified as "no". Subjects could be categorized into one or more themes based on the content of their responses. Each reviewer initially identified and categorized themes for the same 100 randomly selected RPs to assess agreement and to calibrate/standardize the categorization process. Following this, each reviewer independently categorized approximately one-third of the remaining 2,688 free-text responses.

Statistical Analyses

Data were summarized using frequencies and percentages for categorical variables and means and standard deviations for continuous variables. Among the 100 randomly selected RPs who selected "Other" as a reason for declination, we assessed agreement of the categorization of free-text responses across the 3 reviewers using Fleiss' kappa coefficient.[18]

Among all subjects invited for participation, we compared distributions of demographic and clinical characteristics across the 3 response categories (consented, RP, and RNP) using Kruskal–Wallis tests for continuous variables and chi-square tests for categorical variables. The following characteristics were considered: age at invitation, biological sex, race, ethnicity, whether the individual had an established PCP, and rural vs urban residence, derived by patient ZIP code and defined by rural–urban commuting area (RUCA) codes based on data from the 2000 decennial census.[19] For the latter, we defined urban residence as RUCA codes 1–3 (metropolitan area commuting) and rural residence as RUCA codes 4–10 (primary commuting flow within a place of fewer than 50,000 residents). Following these univariate analyses, we examined the independent effects of characteristics on participant response by simultaneously including all in a polytomous (multinomial) logistic regression analysis, modeling the three-level participation response variable as the outcome of interest using generalized (g-) logits to account for the multiple levels of response.

Among the RPs, we examined in turn associations of each of the structured and the free-text–categorized themed reasons for declination with the same demographic and clinical characteristics as described above, using univariate logistic regression models and fitting reason for declination as the outcome and the characteristics of interest as the exposure. Separate models were fit for each reason for declination and each characteristic. Odds ratios and 95% confidence intervals were calculated to determine direction and magnitude of

effect, and logistic regression–based likelihood ratio tests were used to calculate *P* values. Each univariate analysis was followed by a logistic regression analysis that simultaneously included all demographic and clinical characteristics to assess the independent effects of each one of the characteristics on reason(s) of declination. Separate multivariate models were fit for each reason for declination.

RESULTS

As of February 14, 2022, 545,196 individuals had been invited to participate in Tapestry. The mean age at invitation was 54.5 years (SD 17.4), and 55% of individuals were female. Eighty-six percent of individuals were White, and 91% were non-Hispanic. Forty percent of individuals had an established PCP, and 26% were classified as rural residents.

Of individuals contacted, 38,088 (7.0%) had consented as of February 14, 2022, 12,705 (2.3%) were classified as RPs, and 494,403 (90.7%) were classified as RNPs. Associations of demographic and clinical attributes with consent status are provided in Table 1. In univariate analyses asking whether demographic characteristics differed across the 3 consent groups, compared with consented subjects, RPs tended to be older at invitation; were more likely to be male, non-White, and Hispanic; were less likely to have an established PCP; and were more

TABLE 1. Associations of Consent Status With Demographic and Clinical Characteristics Among the 545,196 Individuals Invited to Participate in the Tapestry Study as of February 14, 2022

	Decliners, reason(s) provided (n=12,705)	Decliners, no reasons provided (n=494,403)	Consented subjects (n=38,088)	Total (n=545,196)	Univariate *P* value	Multivariate *P* value[c]
Gender, n (%)					<.001[a]	<.001
Female	7,289 (57.4%)	265,485 (53.7%)	24,624 (64.7%)	297,398 (54.5%)		
Male	5,416 (42.6%)	228,868 (46.3%)	13,462 (35.3%)	247,746 (45.4%)		
Mean age at invitation years (SD)	61.0 (16.0)	54.3 (17.5)	55.1 (15.7)	54.5 (17.4)	**<.001**[b]	**<.001**
Race, n (%)					**<.001**[a]	**<.001**
White	11,444 (90.1%)	422,600 (85.5%)	34,820 (91.4%)	468,864 (86.0%)		
Black/African-American	347 (2.7%)	27,363 (5.5%)	932 (2.4%)	28,642 (5.3%)		
Asian	450 (3.5%)	19,477 (3.9%)	1,111 (2.9%)	21,038 (3.9%)		
AI/AN/NH/OPI	57 (0.4%)	3,738 (0.8%)	189 (0.5%)	3,984 (0.7%)		
Unknown/unspecified	407 (3.2%)	21,225 (4.3%)	1,036 (2.7%)	22,668 (4.2%)		
Ethnicity, n (%)					**<.001**[a]	**<.001**
Non-Hispanic	11,811 (93.0%)	447,223 (90.5%)	35,493 (93.2%)	494,527 (90.7%)		
Hispanic	475 (3.7%)	30,547 (6.2%)	1,873 (4.9%)	32,895 (6.0%)		
Unknown/unspecified	419 (3.3%)	16,633 (3.4%)	722 (1.9%)	17,774 (3.3%)		
Established PCP, n (%)					**<.001**[a]	**<.001**
No	7,334 (57.7%)	301,339 (61.0%)	20,574 (54.0%)	329,247 (60.4%)		
Yes	5,371 (42.3%)	193,064 (39.0%)	17,514 (46.0%)	215,949 (39.6%)		
Residence					**<.001**[a]	**<.001**
Urban	9,417 (74.1%)	362,434 (73.3%)	30,374 (79.8%)	402,225 (73.8%)		
Rural[d]	3,285 (25.9%)	131,931 (26.7%)	7,712 (20.2%)	142,928 (26.2%)		

[a]Chi-square test assessing individual association of consent status with characteristic of interest.
[b]Kruskal–Wallis test assessing individual association of consent status with characteristics of interest.
[c]Multivariate logistic regression analysis, assessing association of consent status with characteristics of interest after accounting for the effects of the other characteristics. *P* values <.05 are denoted in bold.
[d]Rural defined as living in rural–urban commuting area (RUCA) codes 4–10 (primary commuting flow of fewer than 50,000 residents).
AI, American Indian; AN, Alaska Native; NH, Native Hawaiian; OPI, Other Pacific Islander; PCP, primary care provider.

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likely to reside in a rural location ($P<.001$ for each). Multivariate logistic regression analyses reexamining characteristics after accounting for the effects of the other characteristics yielded similar results.

Among the 12,705 RPs, hypotheses asking whether demographic and clinical characteristics differed across the 5 prespecified structured reasons for declination can be found in the Figure and Supplemental Tables 1–5 (available online at http://www.mcpiqojournal.org). RPs who said they declined in part due to disinterest were more likely to be older at invitation and living in a rural residence. Declination due to concerns about genetic results being included in medical records was more common in males, in those with a PCP, and in rural area residents. Younger and non-White individuals were more likely to have listed insurance concerns as a reason for declination, although this age effect attenuated to null after multivariate adjustment. Declination due to discomfort with medical genetic research was more common among females, younger and White individuals, those with an established PCP, and

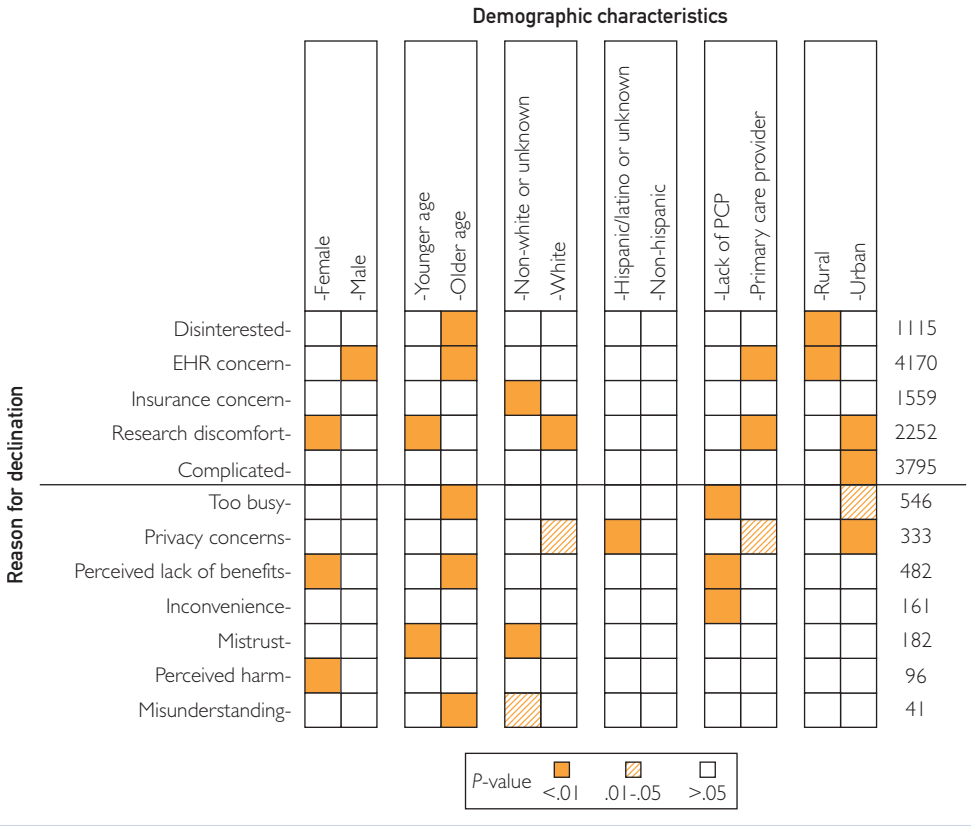

FIGURE. Among 12,705 Tapestry decliners who provided reasons for declination as of February 14, 2022, multivariate-adjusted associations of demographic and clinical characteristics with specific reasons for declination. Demographic characteristics displayed as columns (pairwise comparison), reasons for declination, and numbers of individuals listing that particular reason as rows. For a given reason and demographic subgroup, solid fills indicate the subgroup was significantly more likely ($P<.01$) to decline for that reason than its counterpart, and oblique line fills indicate association based on $P=.01$ to.05 (Supplemental Tables 1–12, available online at http://www.mcpiqojournal.org, provide more specifics on associations). Rural defined as living in rural–urban commuting area (RUCA) codes 4–10 (primary commuting flow of fewer than 50,000 residents). EHR, electronic health record; PCP, primary care provider.

TABLE 2. Participant-Reported Free-Text Reasons for Declining Genomic Study Enrollment: Including Thematic Summary With Examples

Category	Subcategory and examples
Too busy	Too busy due to personal health issues, prior time commitments, or because they are participating in other studies. Example: "Unfortunately at this time my schedule is too tight to be able to commit to an appointment. Maybe timing will be better in the future."
Privacy concerns	General privacy concerns related to personal autonomy or specific privacy concerns with the medical organization, database organization, or insurance companies that may lead to insurance discrimination. Example: "I feel this is an important study, however, I am reluctant to have my personal information out there for someone to hack into."
Perceived lack of benefits	No benefit due to age, prior genetic testing completed, unknown family health history, no financial compensation, the belief that the outcome is inevitable regardless of findings, or the patient believing the study is not applicable to them or they received the invitation in error. Example: "I am just not interested at my age about the genetic results and how they would impact my life."
Inconvenience	Inconvenience due to living too far, infrequent computer use or no access to a computer, difficulties with website accessibility or information technology issues, or concerns of too many e-mails from the project. Example: "Now that I no longer live locally, the distance travelling to mayo is too great."
Mistrust	Mistrust of the study design or study principle, government involvement and access, or mistrust of medical organizations. Example: "I do not want unnecessary information in my medical records for the government to have access too."
Perceived harm	Concerns due to the impact that the findings may have on the individual or family. Example: "My genetic findings affecting my children and their decisions and abilities to get insurance"
Misunderstanding	Misunderstanding of information or having further questions. Example: "I don't have much knowledge of what this is all about"

those living in urban areas. Urban residents were also more likely to decline due to the complexity of the enrollment process compared to their rural counterparts. This is not surprising given the urban residents also indicated being "too busy" as a reason to decline participation.

Review of the free-text responses that individuals provided for other reasons for declination revealed 7 main themes: (1) too busy/lack of time; (2) privacy concerns; (3) perceived lack of benefits to receiving genetic results; (4) inconvenience of the process; (5) mistrust of the care provider, the study principles or potential government involvement/access to results; (6) a perceived harm that results may have on self or family members; and (7) a misunderstanding of information provided or unanswered questions (Table 2). Among the 100 randomly selected RPs who provided free-text responses for reasons for declination, agreement across the 3 reviewers regarding the categorization of responses into themes was high (kappa's ranging from 0.69 to 0.96). Associations of the 7 free-text themes with demographic and clinical characteristics are provided in the Figure and Supplemental Tables 6–12 (available online at http://www.mcpiqojournal.org). Older individuals, those without a PCP, and (in multivariate analyses) urban residents were more likely to decline due to time constraints compared to their demographic counterparts. White individuals and those living in urban areas reported declination due to privacy concerns more often than non-White subjects and those living in rural areas. Conversely, non-Hispanic individuals were less likely to decline due to privacy concerns compared to those with undisclosed ethnicity. Perceived lack of benefits was reported more often in females, those of older age, and those lacking a

PCP. Individuals without a PCP were also more likely to decline due to the inconvenience of the enrollment process. Younger individuals and those of White or undisclosed races were more likely to cite mistrust as a reason for declination. Females were far more likely to list concerns about the impact of results in themselves or family members. Finally, although numbers were small, older and non-White individuals were more likely to decline due to a misunderstanding of study information or unanswered questions about the enrollment process.

DISCUSSION

In this analysis of over 545,000 invitees to the Mayo Clinic Tapestry study, we found clear patterns of non-participation in a large-scale genomic study. A small minority actively declined enrollment and provided reasons for declination, while the overwhelming majority passively declined to participate in the study or actively declined but did not provide reasons for declination. Among RPs, both structured and open-ended (free-text) responses revealed a diverse range of concerns, including privacy, emotional burden, mistrust, and logistical challenges, many of which were associated with specific demographic and clinical characteristics. These findings highlight key barriers to inclusive participation in genomic research and underscore the importance of designing equity-focused strategies to improve representation and engagement.

Understanding the reasons behind non-participation in genetic research, particularly among underserved and minority groups, is critical to improve equitable enrollment. Prior studies have shown that common barriers to participation include privacy concerns, skepticism regarding the benefits of participation, distrust toward health care or government entities, emotional burden/discomfort, and apprehension about potential impacts on insurance coverage.[6] Additional challenges, such as limited time due to competing responsibilities,[20] difficulty in understanding research-related information,[8] personal beliefs and views conflicting with the research and/or genetic study goals, and limited accessibility to resources or sites have also been cited as deterrents.[9] Importantly, racial and ethnic minority participants, especially African Americans and Hispanic individuals, often express concerns regarding the misuse of the medical information, experiences of exploitation in research settings, language and communication barriers, and a deep-rooted mistrust influenced by historical injustices in medical research.[8,14,15] These findings align with our study, in which non-White and Hispanic individuals were more likely to fall into the RP group, underscoring persistent underrepresentation in genomic research. As highlighted in prior literature, such disparities often stem from broader sociocultural and structural barriers in health care access and institutional trust.[15]

Our findings demonstrate that patterns of declination are not random but closely tied to individual demographic and clinical characteristics. Older individuals were more likely to decline participation due to disinterest in learning about genetic risk, time constraints, or a perceived lack of benefit, while younger participants more often cited mistrust or discomfort with genetic research, including concerns about the intentions of researchers or potential misuse of their data. These findings highlight concerns that may reflect generational differences in attitudes toward preventive medicine and long-term health planning as one study looking at genetic research participation in patients with multiple sclerosis showed younger patients were more likely to enroll due to optimism about contributing to a potential cure.[21] Older patients may perceive limited personal benefit from genomic testing, influencing their decision to decline.

Sex differences also emerged, with males more likely to decline due to concerns about genomic results being stored in the electronic health record, while females more frequently cited emotional concerns, discomfort with genomic testing, or potential impacts on family members, echoing established patterns in health-seeking behavior, and communication preferences during clinical encounters. Studies have shown that during medical visits, female patients tend to ask more questions, receive more detailed information, and engage in more partnership-oriented communication with physicians compared to male patients.[22] Historically, men have been well

represented in research. Sex-specific analyses, including those involving cardiovascular prevention trials, suggest that men are often more willing to participate than women, primarily due to perceived benefits, whereas women frequently express concerns about potential harm or being subject to experimentation.[23]

In addition to sex differences, our data also revealed significant variation by race and ethnicity. When assessing race and ethnicity demographics in RPs, non-White patients were more likely to decline due to concerns about the impact of genetic results, obtaining life insurance, and a misunderstanding of information. Non-Hispanic patients were more likely to choose disinterest as a reason for declination. The Cancer Genetics Network, which promotes large-scale genetics research, has emphasized strategies to enhance diverse participation. These include developing culturally tailored and accessible materials, framing outreach with hopeful messages rather than focusing on negative health statistics, and engaging communities as collaborators in the research process. Such efforts aim to foster transparency, build stronger trust, and ensure that research protocols are responsive to the specific needs of minority populations.[13] Our data was consistent with other studies whereby participation by minority groups in genomic research is low, particularly with African Americans, Hispanic/Latinos, Native American/American Indians, and rural communities.[8,10,13]

Primary care providers frequently serve as the initial point of contact with the health care system and play a crucial role in facilitating and advancing genetic-based medicine. By reviewing the patient's personal and family history, PCPs can recognize indications for referrals to initiate testing and diagnostic workups for certain genetic conditions.[24] This incongruency of exposure to a PCP could also be a contributing factor to the reflective lack of participation by the same groups in genetic testing research.

To evaluate the impact of having an established PCP on participation in genomic research, we found that individuals with a PCP were likely to decline participation mostly due to concerns about genomic results being included in their medical records or general apprehension about participating in genomic research. Those without an established PCP were more likely to decline due to lack of time, perceived lack of benefit, or inconvenience of the process. Despite an overall positive view on the utility of genomic testing, multiple studies have reported that PCPs feel inadequately prepared to incorporate genomic testing into their routine practice. Common barriers include limited genomic literacy, uncertainty regarding appropriate referral timing, and logistical concerns such as cost and lack of support for counseling and informed consent procedures.[24-26] As Hamilton et al[27] noted, provider discomfort with discussing genomic results and uncertainty around their clinical utility can hinder population-level benefits, despite expanded access to testing. Information sessions for PCPs may increase their confidence in discussing genomic testing with their patients and further improve participation. For patients without an established PCP, it may be more difficult to disseminate information about the study process. Strategies to improve participation in genomics research may include developing educational materials on different platforms, including online videos, brochures, and artificial intelligence agents,[28] to generate awareness.

Finally, we looked at differences between patients based on area codes. Those who lived in rural areas were more likely to decline due to disinterest or concern about medical records, whereas those living in urban areas declined due to genomic research concerns, believing the process is too complicated, lack of time, or privacy concerns. One study has shown rural—urban differences in direct-to-consumer genomic testing. Rural residents were less likely to report awareness of direct-to-consumer testing; however, there was no difference between groups in the source from which they learned about the testing, television and internet being the most common source and health care provider being the least common source.[29] This study may be transferable to genomic testing for research and an opportunity to improve education among providers and those in rural areas.

To our knowledge, with 12,705 responders, this is the largest evaluation of

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non-participation in a genomic study. In addition to the predefined structured reasons, the authors categorized free-text comments into 7 main themes to further delineate the reasons for declination. The limitations of the study include that the vast majority of Tapestry non-participants were RNPs, and we did not have information regarding reason(s) for refusal. Overall, this project involves a large sample size, but there is still a significant underrepresentation of minority racial and ethnic groups. The study did not control for disease burden, so patients with more severe conditions may have been overrepresented due to greater interest.

Our study provides critical insight into why patients decline genomic testing, a perspective that is often studied in efforts to improve participation in genomic research. On the other hand, considering the post-genome sequencing (GS) regret, it is essential to be aware of this phenomenon when designing recruitment strategies and educational materials. A prior study shows that those with low positive and high negative attitudes at the time of GS enrollment are more likely to regret their decision later, highlighting the need to address concerns like privacy and discomfort with genomic research upfront.[30] By knowing more about the patients' concerns and better assessment of their knowledge and attitudes at the time of offering GS, we can strongly support informed decisions and reduce the potential future post-GS regret. Our findings reinforce the need to transition from descriptive assessments of participation to implementation strategies that address barriers at multiple levels, as advocated in recent public health genomics frameworks.[31]

CONCLUSION

This large-scale evaluation of non-participation in a genomic screening initiative underscores the multifactorial nature of declination, influenced by demographic, clinical, and structural factors. Our findings revealed that concerns about privacy, mistrust, perceived lack of benefit, and logistical barriers, particularly among underserved populations, remained as significant obstacles to equitable participation. Enhancing the genomic literacy and engagement of PCPs, addressing structural limitations in rural and minority communities, and supporting informed decision-making at the time of offering the genomic testing are critical to maximizing the reach and utility of genomic medicine. Future genomic research studies should prioritize inclusivity, more transparency, and accessibility to bridge current disparities and minimize long-term regrets associated with participation or non-participation.

POTENTIAL COMPETING INTERESTS

The authors report no competing interests.

ETHICS STATEMENT

This study was deemed exempt by the Mayo Clinic Institutional Review Board under 45 CFR 46.104(d)(4) as secondary research using existing data with no direct participant interaction.

SUPPLEMENTAL ONLINE MATERIAL

Supplemental material can be found online at http://www.mcpiqojournal.org. Supplemental material attached to journal articles has not been edited, and the authors take responsibility for the accuracy of all data.

Abbreviations and Acronyms: **GS**, genome sequencing; **PCP**, primary care provider; **RUCA**, rural–urban commuting area

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