Participation in genetic research among Latinx populations by Latin America birth-residency concordance: a global study

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Abstract

Latinx populations are underrepresented in DNA-based research, and risk not benefiting from research if underrepresentation continues. Latinx populations are heterogeneous; reflect complex social, migration, and colonial histories; and form strong global diasporas. We conducted a global study using a survey tool (Amazon's Mechanical Turk portal) to ascertain willingness to participate in genetic research by Latin America birth-residency concordance. Participants in the global study identified as Latinx ($n=250$) were classified as the following: (1) born/live outside of Latin America and the Caribbean (LAC), (2) born within/live outside LAC, and (3) born/live within LAC. Latinx were similarly likely to indicate they would participate in DNA-based research as their non-Latinx counterparts (52.8% vs. 56.2%, respectively). Latinx born and living in LAC were significantly more willing to participate in DNA-based research than Latinx born and living outside of LAC (OR: 2.5; 95% CI: 1.3, 4.9, $p<.01$). Latinx indicating they would participate in genetic research were more likely to trust researchers ($<.05$), believe genetic research could lead to better understanding of disease ($<.05$), and that genetic research could lead to new treatments ($p<.05$) when compared with Latinx not interested in participating in genetic research. In summary, significant variation exists in genetic research interest among Latinx based on where they were born and live, suggesting that this context itself independently influences decisions about participation. Cultivating and investing in a research ecosystem that addresses, values, and respects Latinx priorities, circumstances, and researchers would likely increase research participation and, even more importantly, potentially impact the inequitable health disparities disproportionately represented in Latinx communities.

Keywords Latinx · Hispanic · Research participation · Genetic · Genomic · Latin America · Attitudes · Social determinants · Diaspora

Introduction

Genetic and genomic research has expanded exponentially over the past decades, shaping new paradigms and approaches

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to prevention, diagnosis, treatment, and prognosis of disease (Collins and Varmus 2015). Underlying these new approaches is the use of genomic information obtained through advanced gene sequencing technologies to improve health outcomes globally. DNA-based research must prioritize inclusion, equity, and diversity in order to achieve this goal and to contribute towards mitigating and preventing health disparities among historically underrepresented groups (Sirisena and Dissanayake 2017). Wide representation of genomic, environmental, sociocultural, ethnic, and ancestral diversity in genetic/genomic research supports discovery of important insights that could directly impact the development of health interventions (e.g., biomarkers, treatments) and health outcomes (Popejoy 2019a, 2019b; Wojcik et al. 2019). DNA-based research in underrepresented populations, however, has often resulted in research misconduct (Chadwick et al.

2019; Claw et al. 2018; Garrison 2013), promotion of discriminatory theories and actions (Chaturvedi 2001; Roberts 2011; Wensley and King 2008), and exaggerated benefit (Montoya 2011; Sankar 2006). Around the world, DNA-based research overwhelmingly reflects populations with predominantly European ancestry, and other groups including Latinx¹ significantly underrepresented (Mills and Rahal 2019). The proportion of non-European descendants' participation in genome-wide association studies (GWAS) studies has increased by an increment of 80% in individuals of Asian descent, whereas in the past decade, participants of Latinx ancestry still represent less than 1% of the studied participants (Mills and Rahal 2019; Popejoy and Fullerton 2016). Similarly, while the number of African American and Afro-Caribbean GWAS participants quadrupled in 2017 compared to the preceding decade, their total combined proportion remains less than 2% in these studies (Mills and Rahal 2019).

The complex admixture of Native American, European, and West African populations in the genetic makeup of many Latinx populations (Bryc et al. 2010; González Burchard et al. 2005) represents a key element and opportunity to ensure that genetic and genomic research will better serve its goal. Regional ancestry differences among Latinx groups across distinct geographical areas and eras, inside and outside the USA, might contribute to differences and gradients in health outcomes and risk of disease (Bryc et al. 2015; Conomos et al. 2016; Salzano and Sans 2014). For instance, GWAS studies in prostate cancer have been disproportionately conducted in European and Asian descendants and have identified specific genetic risk variants. Different and significant risk variants, however, were recognized to be present mostly in Latinx populations (Du et al. 2020). Research with Hispanic and Latinx women led to the identification of the role of specific gene loci, including the 6q25 locus, as protective in breast cancer (Fejerman et al. 2012; Hoffman et al. 2019). Certain Latinx groups, such as Puerto Ricans, show higher asthma morbidity and mortality rates as compared to other ethnic groups (Centers for Disease Control 2020, October 26; Keet et al. 2015). GWAS studies have identified genetic variants that potentially explain some of the vulnerability of the Puerto Rican population (Yan et al. 2017).

Evaluation of genetic risk through GWAS research in Latinx — and other — populations could serve multiple populations with greater understanding of DNA-based elements of disease, and the treatments and preventive actions that could arise from such insights (George et al. 2014; Oh et al. 2015). Enrollment, recruitment, and retention of Latinx

populations in biomedical research, however, has been challenging in the USA. For example, from 2003 to 2016, only 2.6% of the registered cancer clinical trials participants were Latinx and the enrollment fraction reported was 0.4% as compared to non-Hispanic whites (Duma et al. 2018). The Hispanic Community Health Study/Study of Latinos (a large cohort study of Latinx US residents from Mexico, Puerto Rico, Cuba, Dominican Republic, Central and South America) successfully enrolled only 41.7% of the screened and eligible subjects (Barr et al. 2016). Retention of individuals in clinical trials, such as antihypertensive drug trials, has also been lower for Latinx participants compared with non-Hispanic individuals (59.3% vs. 70.5%, respectively) (Hernandez et al. 2018; Margolis et al. 2007). In GWAS, 5.1% of the studies and 1.1% of the participants were from Hispanic/Latin American populations (Sirugo et al. 2019).

We conducted this study to better understand determinants of intent to participate in genetic research among people who identify as Latinx, with a particular focus on country of birth-country of residence concordance/ discordance as a social determinant. Specifically, we intended to ascertain how rates of intent to participate in genetic research varied in three categories: Latinx born and live in the same Latin American country, born in a Latin American country and migrated to another country, and Latinx ethnicity but born and live outside of Latin America.

Methods

The theoretical basis of this study is the Integrated Behavioral Model, which blends elements of the Theory of Planned Behavior and the Theory of Reasoned Action (Montaño and Kasprzyk 2015). Our core interest is learning more about determinants of participation in genetic research to inform recruitment and retention designs that include a wider group of potential participants in genetic research efforts. As such, at its base, understanding participation in genetic research is a function of a population's cumulative beliefs and experiences with research, genetics, and their contributions, tempered by decision-making drivers, psychosocial norms and environment, and perceptions of impact.

Study design

We conducted an analytic cross-sectional study to ascertain determinants of willingness to participate in genetic research by Latinx birth-residential classification nested within a parent study focused on global attitudes and practices around genetic testing and genetic research. We adhere to the *REporting of studies Conducted using Observational Routinely-collected health Data* (RECORD) checklist (Benchimol et al. 2015) in presenting the results of this study.

¹ In this paper, the co-authors have decided, generally, to use "Latinx" as an ungendered umbrella term to describe people who identify culturally, politically, or ancestrally with the peoples and nations of the Latin American and Caribbean region. We understand this is an imperfect term to describe a very wide range of communities but feel it most appropriately matches our intentions among the alternatives.

Setting

The parent study for this project used the Amazon Mechanical Turk (MTurk) portal to access its cloud-based digital and global workforce. The MTurk portal has been shown to be a reliable method for reaching a global audience for survey research (Bentley et al. 2017). MTurk offers benefits such as speed, access to regions distant from the investigator, the ability to target respondents in specific countries and states, and institutional filters and screens from the MTurk worker qualification process that can improve sample selection without reducing data quality when compared with other modalities (Keith et al. 2017). We recruited participants using materials (see [supplementary materials](#)) in English and in Spanish in three waves starting in January 2015 and ending in October 2017 with compensation ranging from US\$0.25 (for example, for early English-language responders) to US\$1.00 (for example, for later Spanish-language responders) as the study progressed. Advertisements and links to the MTurk survey were placed through Facebook, LinkedIn, Twitter, and Reddit social media sites. We used MTurk's Local Qualification variable (country of residence for which a potential participant's account is registered) as a filter for eligibility for a particular country or region's survey. Inclusion criterion was limited to individuals aged 18 and over who read English or Spanish.

Survey instrument

A survey was assembled to ascertain the main variables of the parent study relating to attitudes and experiences of both genetic testing and of participation in genetic research (see [Supplementary Material](#)). A pilot study of the survey was conducted with 104 participants (all ethnicities) from around the world to provide insight on flow, wording, timing, and variable distribution. The survey was deployed directly in the Amazon MTurk interface, and participants were required to review the Information Sheet and to consent before continuing.

The survey ascertained demographics, including age, gender, material assets (car and home ownership), education, birth country, and residential country. It also assessed beliefs about genetic research (adapted from Skinner et al. (2008) and Wenzel et al. (2008)), concerns about genetic research (adapted from Olsen et al. (2008)), genetic testing beliefs and experience (Olsen et al. 2008), ethics position (from Forsyth's Ethical Position Questionnaire (Forsyth 1980)), and health locus of control (from Wallston's Multidimensional Health Locus of Control (Wallston et al. 1978)).

Definition of genetic research

Our primary dependent variable for this analysis assessed the participant's intent to participate in genetic research. We presented participants with a definition for "genetic research" as implemented in this study:

(English) We would like you to now answer some questions about genetic research. Genetic research is when researchers collect your DNA (through saliva, blood, or other tissues) to explore a link between people's genetic makeup and their risk for certain health outcomes. Please use the options provided to share how likely or unlikely you are to participate in genetic research.

(Spanish) *Quisiéramos que contestara unas preguntas con relación a los estudios genéticos. La investigación genética se lleva a cabo cuando los investigadores obtienen su ADN (de saliva, sangre u otro tejido) y son analizados para explorar la relación entre su composición genética y sus riesgos a desarrollar ciertas condiciones o enfermedades.*

Por favor elija entre las opciones para saber cuan probable o improbable es que usted participe en investigaciones genéticas.

This description of genetic research was followed by the operationalization of the primary outcome variable for this study that ascertains participant likelihood of participating in genetic research, adapted from Green et al. (2006).

(English) I would participate in research that used my DNA

(Spanish) *Participaría en estudios de investigación que utilicen mi ADN*

Participants were provided checkboxes with a 5-point Likert scale as response options (very unlikely, unlikely, neither likely nor unlikely, likely, very likely/*muy poco probable, poco probable, ni probable o improbable, probable, muy probable*).

In addition, three additional secondary clarifications about genetic research participation from Green et al. (2006) were ascertained:

(English) I would participate in research where my DNA was used for something other than the main study goal/ (Spanish) *Participaría en estudios de investigación donde mi ADN se utilice para pruebas no relacionada al objetivo principal del estudio*

(English) I would allow my DNA to be shared with a private company/ (Spanish) *Yo autorizaría a compartir mi ADN con compañías privadas*

(English) I would allow my DNA to be used to create cell lines-these would allow for my DNA to be used in future studies/ (Spanish) *Yo autorizaría a que mi ADN se utilice para crear una línea celular, lo que permitiría que mi ADN pueda utilizarse en estudios futuros*

Definition of Latinx birth-residency concordance

The primary *independent* variable of interest for this study was Latinx Birth-Residency Concordance Status. For the USA version of the survey, we used the OMB-15 (Wallman and Hodgdon 1977) Race and Ethnic Standards for Federal Statistics and Administrative Reporting for participants to self-identify the races with which they identify (with “check all that apply” OMB-15 race options), and (separately) if they identify as “Hispanic” or “Non-Hispanic.” Participants were provided an open-ended response option to explain their self-identification further if they wished. In the global sample outside of the USA — where race and ethnicity identities vary considerably (Morning 2015) — participants were asked in an open-ended question to “Please tell us about your race and ethnicities” or “*Por favor díganos sobre sus raza y etnias.*” All open-ended responses were reviewed and any response indicating the participant considered themselves Latinx (e.g., “Blanco, Hispano,” “Negra, Hispana, Puertorriqueña”) or from a specific ancestral background rooted in an ethnic group or country in Latin America and the Caribbean (e.g., “*Franco Mexicana (padre Francés, madre Mexicana)*”) were coded as “Latinx.” Birth-residency concordance was computed with an algorithm that compared the participant’s birth country and residential country and three categories were included in this study: born and reside in Latin America and the Caribbean (LAC), born in LAC and now reside outside of it, and born and reside outside of LAC. While other combinations are possible (for example, born outside of LAC and now live inside of it), those combinations had too few (or no) participants to create an additional category. The United Nations’ M49 Standard Classification of countries and regions was used to define “Latin America and the Caribbean” for this study (United Nations Statistics Division 2019). Mentioned previously, the consensus of the authorship team is to predominantly use the term “Latinx” in this study to refer to people who identify culturally, politically, or ancestrally with the peoples and nations of the Latin American and Caribbean region, while recognizing this and other such labels may inaccurately insinuate homogeneity populations within this overall term. The authors also recognize the term “Latinx” may not consistently be used among the people included to describe themselves.

Sample size

The parent study — which this nested analytical cross-sectional analysis is within — aimed to detect a 4-point difference in standardized *T*-scores (mean=50, standard deviation=10) in the main attitude indices measured. With 95% confidence and 80% power, the minimum required sample size per region was 120 completed interviews with 20% inflation for missing information and multivariate analyses. For this subanalysis of Latinx residential concordance classification and intention to participate in genetic research, our post hoc power calculation indicated that there was >70% power to detect at least an odds ratio of 2.7 or greater.

Statistical analysis

Chi-square analysis and ANOVA were used to identify statistical significance in bivariate associations for categorical and continuous variables, respectively. We used logistic regression to compute odds ratios (OR) to denote the magnitude (with 95% confidence intervals; 95% CI) of associations, and using Hosmer and Lemeshow’s approach (Hosmer Jr and Lemeshow 2004), identified potential confounders (with $p < .10$ with both the Latinx category and participation in genetic research) to enter into a multivariate logistic model. All variables included in the adjusted models had variance inflation factors (VIF) < 2. We used the goodness-of-fit statistic to estimate how well the data fit the model. SPSS Statistics (IBM Corporation, v25) was used for all analyses. All indices used in this study were analyzed by creating standardized *T* scores with a mean of 50 and standard deviation of 10 following Streiner and Norman’s approach (Streiner et al. 2015).

Ethical review

This study was performed in accordance with the ethical standards established by the 1964 Declaration of Helsinki and its later amendments (General Assembly of the World Medical Association 2014). The University of Rochester’s Research Subjects Review Board reviewed and approved this study (#RSRB00054439) as exempt from federal regulation under Category 2 (Observational Research; 45 CFR 46.101 Federal Human Subjects Regulations). Participants consented to engage in this research after a review of a detailed Information Sheet presented in English or Spanish. All researchers and analysts involved in this study completed research, ethics, and compliance training using the Collaborative Institutional Training Initiative (CITI Program).

Results

In total, 1743 people from 69 countries participated in the survey, 205 opting for the Spanish version, and 1538 opting for the English version. The average time for completion of the final implemented version of the survey was 13.7 min for the English version, with the Spanish version taking an average of 15.2 min. Over 80% of respondents indicated that the survey questions were understandable, the meaning was clear and straightforward, and that the scales used were adequate.

Types/categories of Latinx birth-residence concurrence

Shown in Table 1, similar proportions ($p=0.315$) of respondents self-identifying as Latinx and as non-Latinx indicated they would be likely or very likely to participate in research that used their DNA. Latinx respondents, however, were

significantly ($p=0.04$) less likely than others to be willing to share their DNA with private companies (OR: 0.69; 95% CI: 0.50, 0.96) or to create cell lines for future studies (OR: 0.74; 95% CI: 0.56, 0.99).

Latinx respondents reflected three birth-residential concurrence subtypes (Table 1): (1) more than half of Latinx respondents (56%) were born and lived outside of LAC, (2) 24% were born in LAC but lived outside of it, and (3) 20% of respondents were born in and presently lived within LAC. The majority of the Latinx group born and living outside of LAC were born (94.5%) and lived (97.9%) in the United States of America. Of the group born in LAC but living outside of LAC, 42.6% were from Central America, 34.4% from South America, and 23.0% from the Caribbean regions; most of this group now lived in the United States of America (USA) as well (96.7%). For the Latinx group born and still living in LAC, most were born and still lived in South America (76.9%), Central America (17.3%), and the Caribbean

Table 1 Likelihood of participating in genetic research by Latinx ethnicity and Latinx residential concordance subtypes, mTURK Global Attitudes and Beliefs toward Genetic Testing and Research Study

Participation in research by DNA use scenario	Overall Latinx classification				Latinx grouped by Latin America and the Caribbean (LAC) residential concordance			
	Total (all)	Not Latinx	Total Latinx	Latinx vs. non-Latinx	Born and live outside LAC	Born in LAC, live outside LAC	Born in LAC, live in LAC	Within residential concordance categories
	<i>n</i> =1698 # (col% ¹)	<i>n</i> =1448 # (col%)	<i>n</i> =250 # (col%)	<i>p</i> -value	<i>n</i> =140 # (col%)	<i>n</i> =60 # (col%)	<i>n</i> =50 # (col%)	<i>p</i> -value
I would participate in research that used my DNA (% “Likely/ Very Likely”)	946 (55.7)	814 (56.2)	132 (52.8)	0.315	65 (46.4)	32 (53.3)	35 (70.0)	0.016*
I would participate in research where my DNA was used for something other than the main study goal (% “Likely/ Very Likely”)	597 (35.2)	523 (36.1)	74 (29.7)	.051	42 (30.0)	16 (26.2)	16 (33.3)	0.719
I would allow my DNA to be shared with a private company (% “Likely/ Very Likely”)	458 (27.1)	405 (28.1)	53 (21.3)	.025	30 (21.7)	12 (19.7)	11 (22.0)	0.938
I would allow my DNA to be used to create cell lines-these would allow for my DNA to be used in future studies (% “Likely/ Very Likely”)	677 (40.2)	592 (41.2)	85 (34.3)	.039	42 (30.4)	21 (34.4)	22 (44.9)	0.186
Answered survey in Spanish	205 (11.8)	22 (1.5)	183 (70.9)	<.001	93 (64.1)	57 (93.4)	33 (63.5)	<.001
Born in:								
USA	778 (44.6)	641 (43.2)	137 (53.1)	.003	137 (94.5)	0 (0)	0 (0)	<.001
South America	78 (4.5)	17 (1.1)	61 (23.6)	<.001	0 (0)	21 (34.4)	40 (76.9)	<.001
Central America	37 (2.1)	2 (0.1)	35 (13.6)	<.001	0 (0)	26 (42.6)	9 (17.3)	<.001
Caribbean	27 (1.5)	11 (0.7)	16 (6.2)	<.001	0 (0)	14 (23.0)	2 (3.8)	<.001
Presently live in:								
USA	869 (49.9)	668 (45.0)	201 (77.9)	<.001	142 (97.9)	59 (96.7)	0 (0)	<.001
South America	60 (3.4)	20 (1.3)	40 (15.5)	<.001	0 (0)	0 (0)	40 (76.9)	<.001
Central America	12 (0.7)	2 (0.1)	10 (3.2)	<.001	0 (0)	0 (0)	10 (19.2)	<.001
Caribbean	6 (0.3)	4 (0.3)	2 (0.8)	0.200	0 (0)	0 (0)	2 (3.8)	0.018

¹ Please note that we present column percents in this table, aimed at showing distribution of demographic variables by sample strata.

(3.8%). Additionally, 71% of Latinx respondents answered the survey in Spanish (Table 1).

Sociodemographics and genetic research participation

Shown in Table 2, age, gender, education, and material asset ownership were not significantly associated with likelihood of participating in genetic research among Latinx respondents. Latinx birth-residential concurrence subtype was, however, associated with likelihood of participating in genetic research ($p=0.016$): respondents born and living within LAC were significantly more likely to report they would participate in genetic research than either respondents born in LAC and living outside of it, or respondents both born outside of and living outside of LAC. In particular, those respondents born and living *within* LAC were significantly more likely to indicate willingness to participate in genetic research compared with those born and living *outside* of LAC (OR: 2.73; 95% CI: 1.37, 5.44). Of note, within the United States of America specifically, Latinx respondents were significantly ($p=.037$) less likely to participate in research (46.5%) than the US-born and US-living non-Latinx population (54.5%; data not shown).

Genetic research attitudes, beliefs, and experience

Shown in Table 3, Latinx participants who indicated they would not participate in genetic research had statistically significantly ($p<.01$) stronger negative beliefs about genetic research. In particular, participants indicating they would not

participate in genetic research were significantly more likely not to trust researchers, would think too much about results, saw no benefit to their families, and were concerned about privacy. Similarly, participation in genetic research among Latinx respondents was significantly associated with a range of psychosocial indices. Of all the scales assessed, the aggregate scale of Attitudes toward Genetic Testing (Henneman et al. 2013) items was most strongly associated ($F=82.7$; $p<.001$) with participation in research: overall, respondents interested in participating in genetic research had mean scores, on average, that were 20% higher (i.e., more positive attitude toward genetic testing) than those not interested in participating in genetic research. Participants who scored in the top half of Attitudes toward Genetic Testing scores (i.e., held more positive attitudes) were 2.4 times more likely to indicate they would participate in genetic research than other respondents (73.3% vs. 30.0%, respectively; $p<.001$; data not shown). Similar trends were noted when the two other attitudes and beliefs scores were compared: scores on Skinner et al.'s aggregated Genetic Research Beliefs items (Skinner et al. 2008) were 20% higher (more positive) for respondents interested in participating in research versus others ($p<.001$). Henneman et al.'s composite score of Genetic Testing Experience (Henneman et al. 2013) was similarly higher (19% higher for respondents interested in participating in research compared with others; $p<.001$).

Although Latinx respondents born and remaining in Latin America and the Caribbean had the most positive aggregate scores on all three indices when compared with other Latinx diaspora groups, this difference was significant only for the Genetic Testing Attitudes aggregate scores ($p=.006$; data not

Table 2 Demographic characteristics and likelihood of participating in genetic research (Latinx respondents only), MTurk Global Attitudes and Beliefs toward Genetic Testing and Research Study

Variable	Would participate in genetic research (Latinx respondents only)				
	Yes (<i>n</i> , (%))	No (<i>n</i> , (%))	Total	Chi-square	<i>p</i> -value
Median age (30 years) and below	71 (52.6)	64 (47.4)	135	0	0.995
Age over 30	60 (52.6)	54 (47.4)	114		
Female	67 (54.9)	55 (45.1)	122	3.55	0.315
Male	62 (49.2)	64 (50.8)	126		
Own home	44 (49.4)	45 (50.6)	89	1.39	0.708
Do not own home	83 (55.3)	67 (44.7)	150		
Own or lease car	77 (49.4)	79 (50.6)	156	2.41	0.491
Do not own or lease car	49 (59.0)	34 (41.0)	83		
Education HS or less	11 (45.8)	13 (54.2)	24	0.58	0.443
Education more than HS	120 (54.1)	102 (45.9)	222		
Nativity/residential concordance					
Born and live outside Latin America and the Caribbean	65 (46.1)	75 (53.9)	140	8.47	0.014
Born within and live outside LAC	32 (53.3)	28 (46.7)	60		
Born and live within LAC	35 (70.0)	15 (30.0)	50		

Table 3 Psychosocial indices and likelihood of participating in genetic research (Latinx respondents only), MTurk Global Attitudes and Beliefs toward Genetic Testing and Research Study

Variable	Would participate in genetic research (Latinx respondents only)			
	Yes (mean/ SD)	No (mean/ SD)	<i>F</i>	<i>p</i> -value
Genetic research beliefs				
I don't know enough about genetic studies and what can be done with my DNA to feel comfortable participating	2.83 (1.3)	3.79 (1.0)	42.2	<.001
I do not believe my information would be kept private	3.09 (1.1)	3.78 (1.0)	26.4	<.001
Someone might see what genetic disease I may be at risk for and use the information against me	3.02 (1.2)	3.59 (1.0)	15.6	<.001
Being part of a genetic study might lead to discrimination from jobs, insurance, or access to health care	3.27 (1.2)	3.67 (1.0)	7.6	0.006
There is no benefit to me or my family	2.15 (1.0)	3.00 (1.0)	41.5	<.001
I might think too much about the results	3.04 (1.2)	3.60 (1.1)	14	<.001
I don't trust researchers	2.21 (1.0)	3.09 (1.1)	43.1	<.001
Genetic research could help find new treatments	4.47 (0.8)	3.81 (1.0)	35.2	<.001
It may help my children or future families	4.43 (0.7)	3.80 (0.8)	41.6	<.001
It would help us understand inherited diseases	4.49 (0.7)	3.91 (0.8)	37.9	<.001
Genetic Research Beliefs Index	54.4 (8.3)	45.4 (9.6)	63.4	<.001
Genetic Testing Attitudes Index	55.0 (6.7)	45.2 (10.0)	82.7	<.001
Genetic Testing Experience Index	53.6 (9.2)	45.2 (9.1)	44.6	<.001
Idealism Index	50.7 (9.4)	49.3 (10.8)	1.2	0.28
Relativism Index	51.3 (9.7)	48.5 (10.3)	4.6	0.033
Multidimensional Health Locus of Control "Internal" Index	51.4 (9.3)	48.6 (10.6)	4.6	0.033
Multidimensional Health Locus of Control "Chance" Index	50.0 (11.1)	50.1 (8.8)	0.01	0.914
Multidimensional Health Locus of Control "Powerful Others" Index	51.0 (9.7)	48.9 (10.2)	2.6	0.107

shown). In addition, three particular items on the genetic research beliefs scale significantly differed by residential concordance category: respondents indicating they would participate in genetic research were significantly more likely to trust researchers (<.05; with Latinx born and live outside LAC twice as likely to not trust researchers when compared with the other two groups) believe that genetic research could lead to better understanding of inherited disease (<.05; with Latinx born and live outside LAC less likely to expect better understanding when compared with the other two groups), and think that genetic research could lead to new treatments ($p<.05$; with Latinx born and live outside LAC less likely to expect new treatments when compared with the other two groups) when compared with respondents not interested in participating in genetic research.

Psychosocial factors and genetic research participation

Also shown in Table 3, only the "internal" domain of the Multidimensional Health Locus of Control scale was significantly associated with willingness to participate in genetic research, with those favoring participation having higher internal dimension scores (i.e., stronger beliefs that they

themselves control their own health). Also, respondents who indicated a willingness to participate in genetic research scored higher on the "relativism" dimension of Forsyth's Ethics Position (Forsyth 1980) scale, which suggests stronger support for rejection of rigid social rules guiding decisions.

Concerns about participating in research

Shown in Table 4, Latinx participants who indicated they would not participate in genetic research were more likely ($p<.01$) to have concerns about genetic research, such as privacy and confidentiality of data, family history not protected, and concern about how and where data is kept. While Latinx respondents born and living outside of LAC had the highest rates of these concerns when compared with the other two groups, these differences were not significant (data not shown).

Effect of location on attitudes to genetic research

Table 5 presents odds ratios for participation in genetic research by Latinx residential concordance category. In all models, there was a dose-response relationship between residential group and likelihood of participation in genetic

Table 4 Concerns about participation in genetic research (Latinx respondents only), MTurk Global Attitudes and Beliefs toward Genetic Testing and Research Study

	Would participate in genetic research		Chi-square	<i>p</i> -value
	Yes (<i>n</i> , (%))	No (<i>n</i> , (%))		
I have no concerns (Yes)	55 (66.3)	28 (33.7)	9.4	0.009
I have no concerns (No)	69 (45.4)	83 (54.6)		
Privacy and confidentiality of data (Yes)	79 (45.9)	93 (54.1)	12.1	0.002
Privacy and confidentiality of data (No)	48 (70.6)	20 (29.4)		
My family history may not be protected (Yes)	53 (40.2)	79 (59.8)	20.6	<.001
My family history may not be protected (No)	70 (70.0)	30 (30.0)		
How and where the data will be kept (Yes)	78 (47.0)	88 (53.0)	7.8	0.02
How and where the data will be kept (No)	45 (67.2)	22 (32.8)		

research: those Latinx participants who were born and live outside of LAC (almost all born/living in the USA) were least likely to indicate interest in participating in genetic research, while those participants born and living in LAC most likely to indicate interest in participating in genetic research. Latinx participants who were born in LAC and relocated outside of LAC remained in-between the two other categories (with non-significant statistical associations). Adjusting for Genetic Research Beliefs Score did not impact this relationship, although adjusting for Genetic Test Belief Score decreased the magnitude and significance of the association between residency concordance type and likelihood of participation in genetic research. The goodness-of-fit statistic remained non-significant for all models, suggesting the data fit the models well.

Discussion

Underrepresentation of Latinx groups has been erroneously attributed to a lack of willingness to participate in genetic research and in biomedical research in general (Erves et al. 2017). In this global study, people identifying as Latinx were equally likely to indicate they would participate in genetic research as those who did not identify as Latinx, though subgroups varied sharply in their intentions by birth-residential concordance. Specifically, those respondents born in — and still living in — Latin America and the Caribbean were significantly more likely to indicate they would participate in genetic research when compared with other Latinx birth-residential concordance subgroups. Latinx populations who were not born in nor resided in LAC were least likely to

Table 5 Multivariate analysis of birth-residential concordance and would participate in genetic research (Latinx respondents only), MTurk Global Attitudes and Beliefs toward Genetic Testing and Research Study

Variable	Odds Ratio	95% CI	<i>p</i> -value
Model 1: Unadjusted			
Born and live outside Latin America and the Caribbean	Referent		
Born within and live outside Latin American and the Caribbean	2.0	0.9, 4.5	0.076
Born and live within Latin America and the Caribbean	2.7	1.4, 5.4	0.004
Model 2: Adjusted for genetic research beliefs			
Born and live outside Latin America and the Caribbean	Referent		
Born within and live outside Latin American and the Caribbean	1.5	0.8, 2.8	0.255
Born and live within Latin America and the Caribbean	2.6	1.2, 5.4	0.011
Model 3: Adjusted for genetic testing beliefs			
Born and live outside Latin America and the Caribbean	Referent		
Born within and live outside Latin America and the Caribbean	1.2	0.6, 2.2	0.678
Born and live within Latin America and the Caribbean	1.9	0.9, 4.2	0.076
Model 4: Adjusted for genetic research beliefs and genetic testing beliefs			
Born and live outside Latin America and the Caribbean	Referent		
Born within and live outside Latin America and the Caribbean	1.3	0.6, 2.5	0.514
Born and live within Latin America and the Caribbean	2.0	0.9, 4.5	0.091

indicate they would participate in genetic research. They also had the least positive attitudes toward genetic testing and genetic research, were most distrustful of researchers (nearly twice as often as other groups), and expected the least benefit to society from genetic research. In contrast, LAC-born and LAC-residing respondents had the most positive attitudes toward genetic testing, genetic research, participation in research, and the potential benefits of such research to society.

Other research studies have similarly identified barriers and motivators to participation in genetic and genomic research. Such factors include concerns about sharing information and biological samples (trust/mistrust), desire to obtain relevant personal information from the results of the study (personal utility), adverse emotional responses, level of comprehension about the goals and other research elements, access to information, invitation to research opportunities, language discrimination, and formal education attained, among others (Ceballos et al. 2014; Hamilton et al. 2016; Kinney et al. 2010; Martinez 2016; Nuytemans et al. 2019; Pacyna et al. 2021). In our study, attitudes toward genetic research and toward genetic testing, in addition to experience with genetic testing, were all strongly predictive of willingness to participate in genetic research.

Evidence has shown that acculturation factors such as language, length of residency, and the level of acculturation may influence recruitment, participation, and retention in genetic testing (Heck et al. 2008) and potentially in genetic research. Specifically, lower levels of acculturation in Latinx women decreased the intention to make an appointment for genetic counseling in the next 6 months (Sussner et al. 2009). Additionally, individuals with low English proficiency (Vadaparampil et al. 2006) and those with less time spent in the USA (Hamilton et al. 2016) had less awareness of genetic testing, perhaps reflecting less access to recruitment materials and fewer opportunities to participate. Where a population resides within the diaspora community is an important determinant of participating in research; it may be, as Latinx communities become more integrated into USA-based locations, that their trust of the research and/or medical system shifts, or perhaps altruism decreases. Prior research has shown differences in reasons for volunteerism comparing those from collectivist cultures with those from individualistic cultures (Finkelstein 2010). Furthermore, other social determinants that impact the diaspora community could influence both disease risk and participation in DNA-based research (Shaibi et al. 2020).

People who identify as Latinx comprise a large, significant, culturally heterogeneous group sometimes directly united by the Spanish language, sometimes directly united by geography (Latin America and the Caribbean), and sometimes by both through ancestry and earlier generations. Providing access to Latinx populations in genetic research has proven challenging for researchers, and interventions to increase

representation have had only limited success (Durant et al. 2007; Hindorff et al. 2018; Khan et al. 2020; Yancey et al. 2006). Including Latinx populations in genetic research is necessary — although currently insufficient — to assure potential equitable benefit for diagnostic and treatment innovations resulting from such research. To date, genetic research studies have not typically included — nor focused on — Latinx populations at the rate they are represented in the general population (Sirugo et al. 2019).

The unique social-cultural-political history of Latin America is demonstrated in the complex patterns and admixtures of European, African, and Indigenous genes found in LAC populations. This represents an opportunity for researchers to better understand the genetic basis of health and disease and also to tailor genetically derived treatments for cancer, diabetes, and other chronic diseases that disproportionately impact Latinx people. For example, many Puerto Ricans have a tripartite admixture (Indigenous “Taínos,” European, African) reflecting the colonial heritage on the islands, which we now realize could be related along with social determinants to common chronic diseases experienced disproportionately by them (Lai et al. 2009; Via et al. 2011).

Many factors and experiences influence the likelihood that someone would participate in any research project, and there are additional considerations if the research involves biological tissues or genetic data. In our study, the sharp distinction in likelihood of participating in genetic research by Latinx birth-residential concordance category was somewhat mediated by beliefs and attitudes about genetic research itself. Once beliefs and attitudes toward genetic testing per se were controlled—as distinct from attitudes about genetic research—the significance between Latinx subgroup and likelihood of participating in genetic research did not retain significance. That said, the odds ratio of participation in genetic research for Latinx born and living in LAC after adjustment for these three psychosocial indices remained substantially elevated, perhaps indicating that a true relationship remains even though our study was unable to detect it.

Interestingly, however, support for genetic research — seeing its potential value, participating in it, trusting those who conduct it — was strongest among people who were born and lived in Latin America, with second-generation and greater Latinx diaspora born and living outside Latin America (mostly in the USA) least likely to be supportive. The group born in Latin America who relocated abroad (again, mostly to the USA) was in-between these two extremes of opinion, suggesting that exposure to predominantly USA-based populations, institutions, and expectations may temper intent to participate in genetic research. Often, and from a health outcomes perspective, people born outside of a country who migrate gradually become more like the people in their new country (Schwartz and Unger 2017; Yoshida et al. 2017). The health of future generations of immigrants often becomes similar to

those who have been in the country for far longer (Lee et al. 2013). This is not the effect we observed, however; indeed, we found that people who identify as Latinx and who live in the USA have significantly more negative attitudes toward research and participation in genetic research than USA residents who do not identify as Latinx. The reasons for this difference are not clear, but could involve Latinx social determinants in the USA, historic exclusion from research, bias and discrimination, distrust of medical institutions, or historic research abuses that differentially impacted their communities. Additional research is required to better understand these dynamics and, perhaps, to explore restorative justice interventions aimed at accomplishing community-science-medical reconciliation (Nelson 2016; Oguamanam 2018) (Timmermann 2020). Furthermore, addressing barriers more directly and implementing community-based participatory research (CBPR) interventions in creating and implementing research may also encourage greater representation by Latinx populations (George et al. 2014).

Designing recruitment and retention interventions to address the barriers and facilitators among Latinx populations might increase diversity in genetic research. Community participatory-based research has been shown to improve both the recruitment process and the study completion rates by enhancing the levels of trust among participants from African American and Latino communities (Rhodes et al. 2018; Sankaré et al. 2015). Shaibi et al. designed a process to guarantee access to results for Latinx patients undergoing genetic tests in community-based health centers (Shaibi et al. 2018). This intervention involved a multilevel approach that relied primarily on a Community Advisory Board, which provided feedback in each phase of the study, including the development of recruitment materials. In addition, health care providers, health officials, and other stakeholders were involved in integration procedures to inform patients about their results at a visit with a medical geneticist. Results indicated that 43.8% of the invited participants agreed to a baseline visit for informed consent and 70.4% were enrolled ($n=500$). However, the authors indicated that the program would benefit from supplemental education-based programs to increase awareness of precision medicine. Increasing participation of underrepresented and underserved populations such as Latinx populations in genetic research is important, particularly given their ancestral heterogeneity, as it could contribute to an understanding of how genetic variants protect from or increase risk for disease.

Our study was limited by inadequate power to detect some potentially meaningful differences. Also, MTurk-based research could generate research samples that may not be representative of the global community, or the population of any one nation or region. We aggregated widely different Latinx cultures and communities into one category that potentially obscured any within- or across-nation variation that may exist.

Finally, participation in genetic research as defined in our study is hypothetical rather than reflecting actual participation: it is possible intentions are not reflective of actual participation.

Conclusions

Despite the projected growth in the Hispanic population in the USA of almost 200% by 2060 (Bureau 2017), very few global studies have assessed the likelihood of participating in genetic research by Latinx identity, and none has examined the relative experience of birth-residential subtypes. This study demonstrated that significant variation exists in genetic research interest among Latinx communities as a function of where they were born and live, suggesting that this context itself independently influences decisions about participation.

This core finding may apply to other communities underrepresented in genomic research. Attaining significant representation for underrepresented populations requires effective, continuous, and sustainable strategies, despite — for example — advances in increasing the participation of people of African American descent in genomic research (Mills and Rahal 2019) and the expected improvement in understanding complex diseases by improving the detection of novel genomic variants (Popejoy 2019a, 2019b). Similar to Latinx communities, attitudes toward genetic research in other underrepresented communities (including mistrust and the lack of culturally tailored-interventions) contribute to lower rates of enrollment in genetic studies (Parikh et al. 2019; Still et al. 2014).

Conducting additional qualitative and quantitative research on attitudes and genetic research participation among Latinx communities to identify decision-making criteria is needed so that researchers can better understand the perspectives of these populations, their genesis, and priorities. Cultivating and investing in the development of a research ecosystem that prioritizes, values, and respects Latinx priorities, circumstances, and researchers would likely increase research participation and, even more importantly, impact the inequitable health disparities disproportionately represented in Latinx communities.

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Author contribution TDVD conceptualized the study, curated the data, conducted analyses, acquired funding, led the investigation, and principally authored this report. ZQT contributed the original draft, edited, and

reviewed the final version. JGPR, CVV, DVO, EA, and NRCC edited and reviewed the final draft. IDF, AD, and SWG conceptualized the project, contributed to the investigation, and edited and reviewed the final draft.

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Availability of data and material The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

Code availability Not applicable

Declarations

Ethics approval All procedures performed in this study were in accordance with the ethical standards of the University of Rochester Research Subjects Review Board and with the 1964 Helsinki Declaration and its later amendments. The study was approved by the University of Rochester's Research Subjects Review Board (#RSRB00054439).

Consent to participate All participants in this study provided freely-given, informed consent to participate.

Consent for publication Not applicable

Conflict of interest The authors declare no competing interests.

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