UNIVERSITY OF CALIFORNIA,
IRVINE

Assessing the Impact of Provider-Patient Ethno-Racial and Linguistic Concordance on Knowledge and Attitudes of Underrepresented Populations towards Genetic Counseling

THESIS

submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

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DEDICATION

To

all those who supported, guided, and believed in me

I didn't get here alone.

The longer I live, the more deeply I learn that love--whether we call it friendship or family or romance--is the work of mirroring each other's light. Gentle work. Steadfast work. Life-saving work in those moments when shame and sorrow occlude our own light from view, but there is still a clear-eyed loving person to beam it back. In our best moments, we are that person for another.

James Baldwin

Nothing Personal

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ABSTRACT OF THE THESIS

Assessing the Impact of Provider-Patient Ethno-Racial and Linguistic Concordance on Knowledge and Attitudes of Underrepresented Populations Towards Genetic Counseling

By

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Master of Science in Genetic Counseling

University of California, Irvine, 2024

Professor Fabiola Quintero-Rivera, Chair

Provider-patient ethno-racial concordance describes when a patient is seen by a provider from a similar ethno-racial or cultural background, and can include native language concordance, in which a patient is seen by a provider who can speak their native language. Benefits include improvements to both patients' healthcare outcomes and their perceptions of their care. However, given that 87% of genetic counselors (GCs) are White, many patients do not have access to a concordant GC.

The study assessed public attitudes, understanding, and misconceptions of genetics, medical genetics, and genetic counseling through an online survey. Educational videos (intervention), presented by genetics providers and trainees in English, Spanish and Vietnamese, provided education on these genetics topics and compared post-intervention knowledge and attitudes among randomized participants who watched the video from concordant vs. non-concordant providers.

Participant groups included Hispanic/Latino (n=28), Asian (n=60), and African American (n=42); 68% had College/Graduate education, and for 36%, their preferred language was Vietnamese or Spanish. 41% (n=53) of participants viewed counseling as beneficial but unaffordable (p=0.005). Four common misconceptions were detected across all groups pre-intervention: 1) Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a GC; 2) When a genetic condition is found in a fetus, a GC will recommend an abortion (or termination of the pregnancy); 3) GCs help people choose desirable traits for their future children such as height, hair color, and intelligence; and 4) GCs can change a person's genetic makeup. Statements three and four remained misconceptions post-intervention. Two negative attitudes were expressed: fear of receiving a genetic diagnosis for oneself or a child and the belief that genetic counseling was not affordable. Attitudes about cost improved post-intervention, but attitudes about fear remained.

A significant finding across all language and ethno-racial groups was participants' preference for concordant providers who share those backgrounds, 72% (n=63) and 89% (n=78), respectively. Concordant provider videos positively correlated with improved understanding of genetic counseling in six out of seven statements related to at-home DNA kit results versus clinical genetic tests, availability of GC for those planning to become pregnant, genetic test results aiding in choosing appropriate treatment for illnesses like cancer, GC recommending abortion for genetic conditions found in a fetus, seeing a GC without a family history of genetic conditions, and benefits of GC for adopted individuals or

those with limited family information. These results indicate that the benefits of concordance in provider videos were observed even in the absence of direct interaction.

Future research should focus on developing culturally and linguistically tailored educational materials and exploring optimal recruitment strategies to improve genomic literacy among underrepresented populations.

I. Introduction

1.1 Growth of Medical Genetics and the Genetic Counseling Profession

Genetic counseling is a rapidly growing area of healthcare. The National Society of Genetic Counselors (NSGC) defines *genetic counseling* as "the process of helping people understand and adapt to the medical, psychological, and familial implications of the genetic contributions to disease." Clinical genetic counselors practice in various medical specialties, including oncology, pediatrics, prenatal, cardiac, and neurology. They analyze family medical histories to assess disease risk and suggest appropriate genetic testing and screening options. Furthermore, clinical genetic counselors educate their patients about inheritance, testing, medical management, and disease prevention as well as provide counseling to support their patients in making informed decisions about their health (Resta et al., 2006). In addition to direct patient care, genetic counselors can work in clinical laboratories, research, education, and other realms of healthcare and genetics.

Genetic counseling emerged as a profession in the late 1940s and early 1950s. It evolved from the hereditary counseling clinics established by German eugenicists in the 1920s. These clinics aimed to promote hereditary health through marriage advice and premarital examinations. In Germany and the United States, geneticists and other physicians exploring scientific solutions to social issues, such as crime, poverty, and disease, believed that hereditary factors determined both physical and psychological characteristics, and eugenic principles were integrated into welfare and medical systems long before the rise of Nazism. While modern genetic counseling has evolved far from its

roots, historical ties to eugenic ideologies underscore ongoing ethical considerations in the field (Weindling, 1993).

The first genetic counseling master's training program was established at Sarah Lawrence College in 1969. In the 55 years since, the scientific community's knowledge of genetics has evolved rapidly. Advancements in technology and understanding of genetics have dramatically increased clinicians' ability to offer comprehensive genetic testing and interpret results. With these advancements, genetics has become an integral part of healthcare, and the need for genetic counseling to help patients navigate genetic testing continues to grow.

1.2 Health and Genetic Literacy: One of Many Barriers to Access

While the scientific community's understanding and use of genetics has expanded markedly over the last 50 years, the general public's understanding has yet to follow suit. As genetic testing becomes more widely available and utilized in healthcare, there is a pressing need to narrow this gap in medical genetics knowledge between patients and healthcare providers(Jooma et al., 2019; Madden at al., 2024).

Under-represented groups, including Asians, Blacks, and Hispanic/Latinos, have lower rates of health literacy, including knowledge and awareness about hereditary health concepts, than their non-Hispanic/Latino White counterparts (Buseh et al., 2014; Canedo, et al., 2019; Halbert et al., 2005; Hann et al., 2017; Lemke et al., 2022; Pagán et al., 2009; Singer et al., 2008). A 2006 study of health literacy conducted by the U.S. Department of Education revealed that 36% of Americans have either "basic" or "below basic" health literacy. This increased to 48% in Black Americans, and among Hispanic/Latino Americans,

25% had “basic” health literacy and 41% had “below basic” (Kutner et al., 2006). For Hispanic/Latino patients, preferred language correlates with knowledge, as those whose preferred language is Spanish had less genetic knowledge than those whose preferred language was English (Singer et al., 2004). In one study of Asian, Black, Hispanic/Latino, and non-Hispanic/Latino White Americans, non-Hispanic/Latino White participants were most likely to report having heard of genetic testing, followed by Black, Asian, and Hispanic/Latino participants, respectively. For Hispanic/Latino participants, higher rates of education and length of time since immigration to the United States correlated with higher awareness of genetic testing. Factors positively associated with increased awareness of genetic testing included higher rates of education among Black participants and increased time since immigration for Asian participants (Pagán et al., 2009). Many Vietnamese patients express that lack of information and misinformation can be a barrier to genetic testing, explaining that it is hard to trust something that is not well known. Therefore, lack of information is not only a barrier, but it also contributes to distrust, another barrier to accessibility and uptake of genetics services (Lemke et al., 2022).

The impacts of race and ethnicity on perceptions of genetic counseling are not yet comprehensively understood. In a systematic review, non-White participants demonstrated higher perceived disadvantages and concerns about genetic testing than their White counterparts (Canedo, et al., 2019). Under-represented groups expressed more concern than non-Hispanic/Latino Whites about information from genetic testing being misused and expressed less willingness to undergo genetic testing (Diaz, et al., 2014; Suther & Kiros, 2009). Black and Hispanic/Latino patients are less likely to have the financial resources or insurance coverage needed for genetic testing (N=803), and Black patients are more likely

than White patients to express concern that personalized medicine facilitated by genetic testing would not be financially accessible (N=124) (Diaz et al., 2014; Singer et al., 2004). These findings demonstrate the need for culturally appropriate educational material for populations with limited understanding and mistrust of the medical community due to historical and systemic marginalization.

1.3 Implicit Bias

Implicit bias is the unconscious influence of negative associations about a social group on a person's perception of another individual or group. Implicit biases are often discordant with a person's desired actions or values and manifest without awareness (Fitzgerald & Hurst, 2017). Instead, they reflect prevailing cultural attitudes and stereotypes (Nosek et al., 2007). Thus, individual implicit biases can be viewed as a cognitive reflection of systemic problems.

Some examples of stigmatized groups include members of racially under-represented populations, immigrants, gender and sexually diverse individuals, members of particular age groups, and disabled and mentally ill individuals. In the United States, many marginalized groups face negative stereotyping, especially groups defined by race or ethnicity. In a 2017 study, 31% of White respondents reported that they believed Black people are less hard-working than White people, and 20% reported that they believed White people are more intelligent than Black people (Moberg et al., 2019).

These negative associations on an individual level and systemic level are reciprocally connected and lead to inequity that is slow to abate. In the United States, segregation in

housing and education has remained stable since the 1970s, and disparities in income and wealth have widened since the 1980s (Reardon & Owens, 2014).

Just as the implicit bias at the individual level reflects the views of the public, multiple systemic reviews of implicit bias in healthcare found that healthcare professionals exhibit the same levels of implicit negative attitudes and stereotypes about stigmatized groups as the wider population (Zestcott et al., 2016) (Fitzgerald & Hurst, 2017). In a 2014 study, the majority of nursing and medical students located in the Southwestern United States associated Hispanic/Latino patients with noncompliance, risky health behavior, and barriers to effectively communicating health-related information (Bean et al., 2014). Unfortunately, patients begin to face these biases early in life. Medical providers have even been shown to display equal implicit racial bias against patients who are Black children as they do Black adult patients (Johnson et al., 2017).

Like other healthcare providers, genetic counselors in the United States also exhibit implicit bias (Hagiwara et al., 2023; Lowe et al., 2020; Pollock et al., 2022). The Implicit Association Test (IAT) measures the strength of associations between concepts to detect implicit preferences for one group over another. When a cohort of 73 genetic counselors took the IAT, their mean score was consistent with a moderate degree of implicit pro-White bias (Lowe et al., 2020). In one study, White genetic counselors exhibited their prejudice toward Black patients by describing them, on average, as less medically cooperative than their White counterparts (Hagiwara et al., 2023). Students also observed these biases, as 38% of 100 surveyed 2020 genetic counseling master's program graduates reported experiencing or witnessing their supervisors perpetrate racial insensitivity (Pollock et al., 2022).

1.4 Biases Lead to Health Disparities

A central pillar of medicine is to do no harm. However, a healthcare provider's biases towards their patients can impact the delivery of patient care and cause harm. Implicit racial bias is associated with less emotionally responsive and patient-centered communication (Cooper et al., 2012; Schaa et al., 2015). Another study compared genetic counselors' Implicit Association Test scores with their interactions with simulated patients. Genetic counselors whose scores reflected higher racial bias delivered less individualized communication to Black and Hispanic/Latino patients as compared to their White patients. Their bias affected their patients' interactions as well. Both Black and Hispanic/Latino patients of these counselors disclosed less psychosocial and lifestyle information and asked fewer medical questions than their White counterparts (Lowe et al., 2020).

These differences in care lead to health disparities, defined as preventable negative health outcomes experienced by socially disadvantaged groups that cannot be explained by heredity alone (Hagiwara et al., 2023). Racial health disparities have existed in the United States for generations. These disparities mean that disadvantaged groups experience heavier disease burdens and poorer survival rates (Matalon et al., 2023). Health disparities affect the whole lifespan; from prenatal care and infancy to adults 85 and older, Black Americans have higher mortality rates than White Americans. As options for medical intervention continue to advance, the disparity in care experienced by individuals of socially disadvantaged backgrounds has also broadened. For example, heart disease has remained the number one cause of death for Americans since the 1920s. Since the 1950s, heart disease-related deaths have decreased overall; however, the death rate has decreased

more significantly for White patients than their Black counterparts, creating a wider gap in health disparities for heart disease today than 70 years ago (Anderson, 2012).

Racial health disparities exist in management of cancer, heart disease, and neurodegenerative disease, as well as many other conditions for which patients may see a genetic counselor (National Academies of Sciences, Engineering, and Medicine, 2017). For instance, Black Americans are more likely to die from cancer than White Americans despite the genetic contributions to these diseases being similarly distributed across racial groups (American Cancer Society, 2019). Without addressing these implicit biases, advances in medical genetics may further widen health inequities and perpetuate the systemic discrimination underlying these disparities (Matalon et al., 2023).

1.5 Health Disparities and Bias are Felt by People of Color

Genetic counselors' implicit racial biases affect their patients' perceptions of the care they receive. Lowe et al. observed that counselors with higher rates of implicit bias displayed less individualized communication when counseling minority clients (Lowe et al., 2020). Patients whose providers scored higher on measures of implicit bias exhibited lower levels of trust, engagement, and adherence to treatment in clinical settings (Zestcott et al., 2016). One negative interaction with a healthcare provider can often shape a patient's trust toward all future providers. In a 2014 study, Black individuals were asked to self-report if they experienced discrimination in the past 12 months. A strong positive correlation was found between self-reported discrimination and concern about the use of personal genetic information in healthcare (Diaz et al., 2014). In general, Black and Hispanic/Latino patients are less likely to trust that their medical doctor will keep their medical information private

as compared to their White counterparts (Suther & Kiros, 2009). In several studies, Black participants expressed skepticism of genetic testing due to concerns regarding the privacy of their results, possible misuse of genetic information, and fear of discrimination based on their results (Diaz al., 2014; Singer et al., 2004). Black patients reported less trust in American medical institutions and individual providers than other ethno-racial groups (Singer et al., 2004). In the field of genetics, a lack of trust in healthcare providers has been linked to lower rates of testing, increased disparities in health outcomes, reduced rates of diagnosis, and overall poorer health outcomes. This mistrust significantly contributes to the perpetuation of health disparities in genetics. For instance, women from medically underserved racial and ethnic groups who have reservations about the potential misuse of genetic testing are less inclined to undergo genetic testing for further assessment of cancer risk. Consequently, many individuals at high risk are less likely to be identified for early cancer screening, which is known to enhance survival rates. This exacerbates the existing disparities in cancer survival rates among different populations (Thompson et al., 2003).

1.6 Historical Antecedents of Mistrust of Genetics and Medical Research

The inclusion of a diverse range of individuals in medical research is essential for addressing health disparities. However, participation of historically underrepresented racial and ethnic backgrounds (underrepresented minorities, or URM) in medicine is low in many research studies, revealing a widespread skepticism and distrust of medical research, largely stemming from historical unethical practices. This mistrust is further exacerbated by ongoing disparities in healthcare access and outcomes, perpetuating a cycle of fear and

skepticism. Efforts to address this distrust must acknowledge its historical origins, beginning with the inception of the genetic counseling profession.

The hereditary counseling clinics of the 1920s evolved after World War II with the emergence of genetic counseling in the late 1940s and early 1950s, and significant efforts were made to distance genetic counseling from eugenics. However, some geneticists still regarded eugenic goals as compatible with disease prevention, as eugenicists believed that reproduction was both a private matter and a social concern (Iredale, 2000; Paul, 2011; Weindling, 1993).

The term "eugenics" originated in 1883 and was coined by Francis Galton, who drew upon concepts from Gregor Mendel's genetics and Charles Darwin's evolutionary theory. Eugenics evolved from the promotion of healthy reproduction to the eradication of "inferior" traits among the population through racial segregation and forced sterilizations. In the late 1930s and early 1940s, this culminated in the extreme racial hygiene programs of the Holocaust, which forced sterilization, experimentation, and euthanasia on millions of individuals deemed undesirable. Although less well-known today, these ideals were also practiced in the United States through race-based internment camps in the 1940s and the forcible sterilization of Indigenous women throughout the 20th century (Iredale, 2000; Paul, 2011; Weindling, 1993).

Early genetic counselors provided recommendations that often reflected the prevailing assumption that disability should be avoided and prevented (Paul, 2011). In the seven decades since, debates about the role of genetics in shaping societal norms and policies are ongoing. This historical context is crucial to attempt to understand the

skepticism and distrust of genetic counseling among certain under-represented groups and address health disparities.

Beyond genetic counseling, many unethical research practices in the United States' history have contributed to URMs' distrust of medical research. From the 1930s to the 1970s, Black male sharecroppers with syphilis were enrolled in the Tuskegee experiment without their informed consent. Researchers recorded the natural history of syphilis by withholding known and readily accessible treatment as the men suffered severe physical and mental health outcomes and eventually died. In 1951, the cancer cells of a Black woman named Henrietta Lacks were obtained without her knowledge or consent; cell cultures from this specimen are still used today by The Johns Hopkins University Hospital in numerous research endeavors. From the 1950s to 1960s, John Rock and Gregory Pincus tested hormonal birth control pills on women in Puerto Rico without informing them that the drug was still experimental or informing them of known harmful side effects (Whelan, 2020).

URMs' concerns regarding exploitation and mistreatment by medical researchers are rooted in countless instances of blatantly unethical practices, highlighting a critical need for intervention. Efforts to address these distrusts must acknowledge the historical events that precipitated them and emphasize actively involving community advocates to foster transparent and respectful relationships between researchers and URM communities.

1.7 Racial Concordance and Health Outcomes

It is well documented that doctor-patient race concordance positively impacts patients' perceptions of healthcare (Cooper et al., 2003; Johnson et al., 2004; Laveist & Nuru-Jeter, 2002; Saha et al., 1999). Doctor-patient race concordance describes when a patient is seen by a provider from a similar racial, ethnic, and/or cultural background. In several studies, Asian, Black, and Hispanic/Latino patients have reported greater satisfaction with care when seen by a provider of the same race or ethnic background than a different background (Cooper et al., 2003; Johnson et al., 2004; Laveist & Nuru-Jeter, 2002; Saha et al., 1999). High rates of racial concordance were observed when patients were able to choose their provider, particularly in Hispanic/Latino and Asian Americans who had recently immigrated to the U.S. and were not yet comfortable communicating in English (Han & Lee, 2016; Nimbal et al., 2016).

There is also a body of evidence illustrating that provider-patient race concordance has positive effects on patients' perceptions and contributes to a more effective therapeutic relationship and improved healthcare outcomes. These improvements include better communication and shared decision-making, greater time spent with physicians and decreased wait times for treatment, improved patient understanding of disease risk, improved medication adherence, improved cancer screening, and lower healthcare expenditures (Jetty et al., 2021). The benefits of provider-patient racial concordance are often strikingly concrete. For example, Black newborns have lower mortality rates when they are cared for by a Black provider than by a non-concordant provider (Greenwood et al., 2019).

1.8 Importance of Language Concordance

Language concordance is another vital factor of racial and ethnic concordance. Hispanic/Latino and Asian patients report the lowest levels of satisfaction with their doctor's listening and communication skills (Han & Lee, 2016). Spanish-speaking genetic counselors (n=36) believe language concordance positively influences relationship-building and communication (de Leon et al., 2021, 2022). Research indicates that Spanish-speaking genetic counseling patients agree with this belief, as they report that sessions with a native Spanish-speaking genetic counselor, as opposed to one with a translator, made them feel more adequately informed, comfortable asking questions, and supported in their decision-making (Jimenez et al., 2022).

When a native-speaker provider is unavailable, a medical interpreter is an essential tool widely utilized in our healthcare system given that only 4% and less than 1% of genetic counselors report being able to speak Spanish or Vietnamese, respectively (NSGC, 2024). However, culture bumps have been documented to be noticed by providers, patients, and interpreters themselves. Culture bumps describe an event where two individuals from differing cultures have different and possibly conflicting behavioral expectations. This difference in expectation results in an interaction that can be both awkward and uncomfortable for all parties involved. A survey of Spanish interpreters reported culture bumps in topics such as exchanging information, gender and family dynamics, and incorporation of religious and faith beliefs (Rosenbaum et al., 2020).

1.9 Purpose of the Study

Bias is inherent in life; thus, its appearance in healthcare is unsurprising. Rather than focusing solely on eradicating bias in healthcare, it is critically important to acknowledge and address bias and its effects on patients. The goal is to ensure that patients receive culturally competent care from all healthcare providers, and efforts to address and minimize implicit bias in healthcare are in progress. However, there is still insufficient research to assess the efficacy of current cultural competency training and strategies aimed at reducing implicit bias. On average, 2020 genetic counseling program graduates reported their diversity coursework as significantly less effective than their other program coursework (Pollock et al., 2022).

In the meantime, historically and currently marginalized groups (URMs) must receive adequate health care. Given that nearly 90% of genetic counselors are White and White genetic counselors display implicit prejudice towards patients of color, patients from URM groups are likely to interact with genetic counselors who hold implicit bias towards them (Hagiwara et al., 2023; Lowe et al., 2020; NSGC, 2024; Pollock et al., 2022).

The existing literature suggests that one way to improve URMs' healthcare experience is through the availability of racially concordant providers. The American College of Medical Genetics and Genomics (ACMG)'s recent statement emphasizes the importance of recruiting more diverse genetics providers, asserting that doing so will help alleviate medical mistrust, address clinician bias, and provide more accessible and culturally competent care and research opportunities (Madden et al., 2024; Matalon et al., 2023).

This study aims to assess the general population's understanding of medical genetics and genetic counseling, focusing on groups with lower rates of awareness and

understanding (Buseh et al., 2014) (Canedo, et al., 2019). Secondly, we aim to educate the public, particularly these groups that have historically been undereducated on these topics, using informational videos about genetics and genetic counseling delivered by real genetic counselors, a genetic counseling student, and medical geneticists. Finally, using the educational videos, we will assess the differences when a patient from an URM group is seen by a White provider vs. a racially concordant provider, by providing participants with educational materials delivered by concordant vs. non-concordant providers and comparing their educational outcomes.

II. Methods

2.1 IRB Protocol

This research protocol was determined to be exempt using the Institutional Review Board of the University of California, Irvine (UCI) Exempt Self-Determination form. A letter of confirmation for the self-determination process from the UCI Human Research Protections Program (HRPP) can be found in Appendix A.

2.2 Recruitment

From February 8, 2024, to April 12, 2024, seven iterations of participant recruitment flyers, available in English, Spanish, and Vietnamese (Appendix B) were posted on five online forums: NSGC Spanish Development Special Interest Group Community Board, Instagram, Facebook, LinkedIn, and Reddit. Emails with the recruitment flyer, a brief description of the study, and a link to the anonymous online survey were also sent to over 20 organizations (Appendix C) focused on Black, Hispanic/Latino, and Vietnamese people across the United States. The study team requested that the recipients of these materials distribute the study invitation within their organizations. Physical copies of the flyers were posted in public spaces, including street corners and public bus stops in Orange, Garden Grove, Fountain Valley, and Santa Ana, California. On March 8, 2024 and March 12, 2024, the lead researcher presented this project and shared recruitment materials with health educators at the 2024 CHOC and UCI Rare Disease Symposium & Family Conference (350 registered attendants) and at the UCI Chao Cancer Center,

respectively. The data used for this analysis was downloaded from Qualtrics on April 12, 2024; however, the survey will remain open until June 14, 2024 for future further analysis.

2.3 Consent

Implied informed consent was obtained from respondents before they participated in the survey. A study information page was displayed to the respondents before viewing the survey. Reference Appendix D for the study information page contents. By clicking on the "Agree" button at the bottom of the study information page, participants indicated that they consented to participate in the study.

2.4 Survey Design

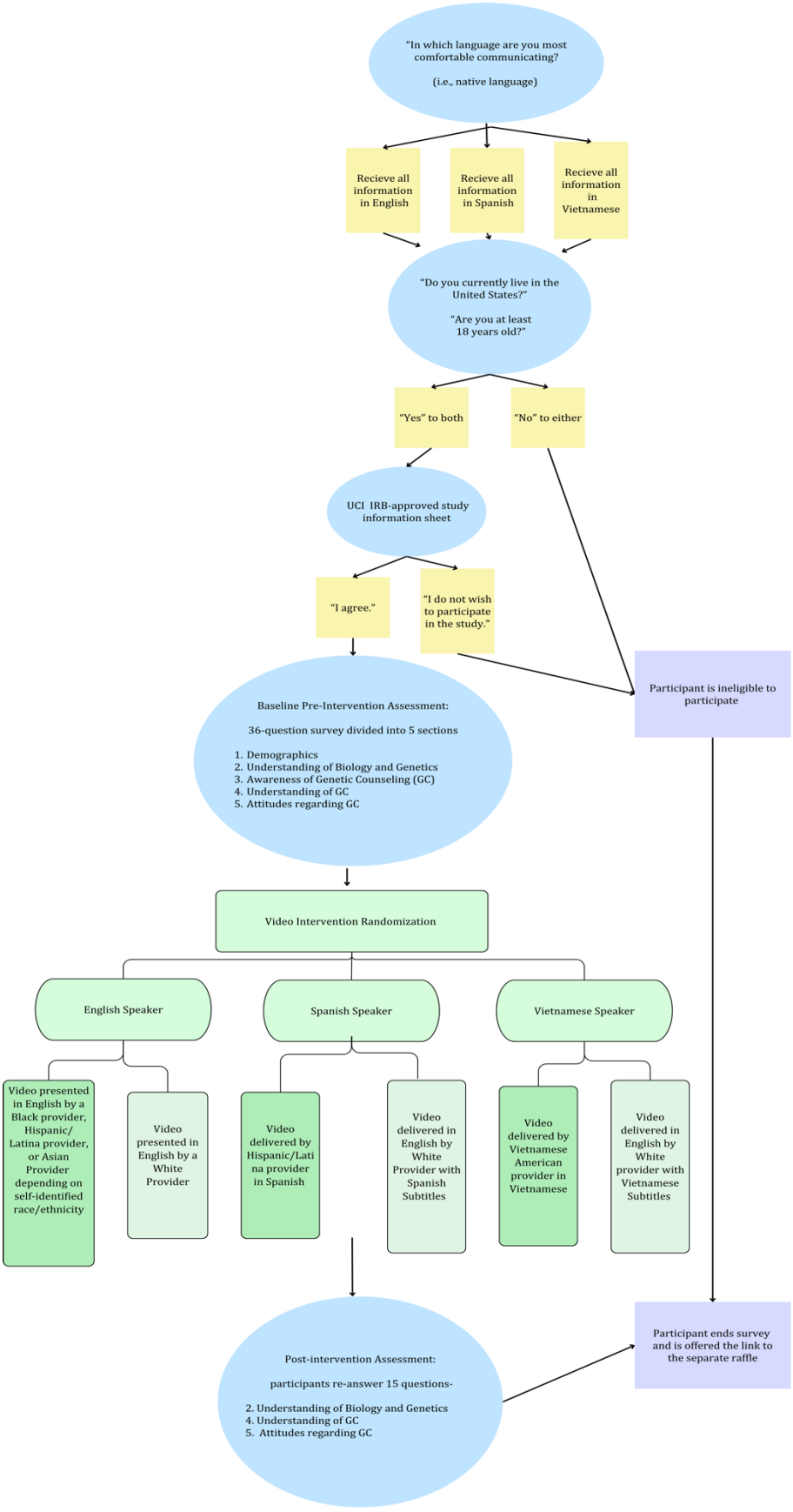
A 36-question anonymous online survey (Appendix E) was created through UCI's Qualtrics XM system and opened to participants on February 8, 2024. The survey included multiple-choice questions, matrix tables, and free-response text boxes. Three questions were embedded with branch logic to enable participants to further elaborate on their responses, if applicable (Table 1). The survey was available in English, Spanish, and Vietnamese and was written by the study team for a seventh grade reading level. Statements were entered into ChatGPT v. 3.0 to assess reading level.

Participants were given the opportunity to enter a raffle for one of 10 $25 gift cards to their choice of Amazon, Starbucks, or Target by providing their email address in a separate Qualtrics survey. Participants were provided the link to enter the drawing when they quit the survey at one of three points: after incorrectly answering the eligibility questions, after choosing not to consent to the study, or after completing the survey. Email

addresses were collected and stored separately from survey responses and were used to distribute compensation. The NSGC Spanish Development Special Interest Group's Rompiendo Barreras Grant funded the gift cards. This award provides funding for projects that focus on the provision and study of the Spanish language in genetic services and research efforts targeted toward the Hispanic/Latino community.

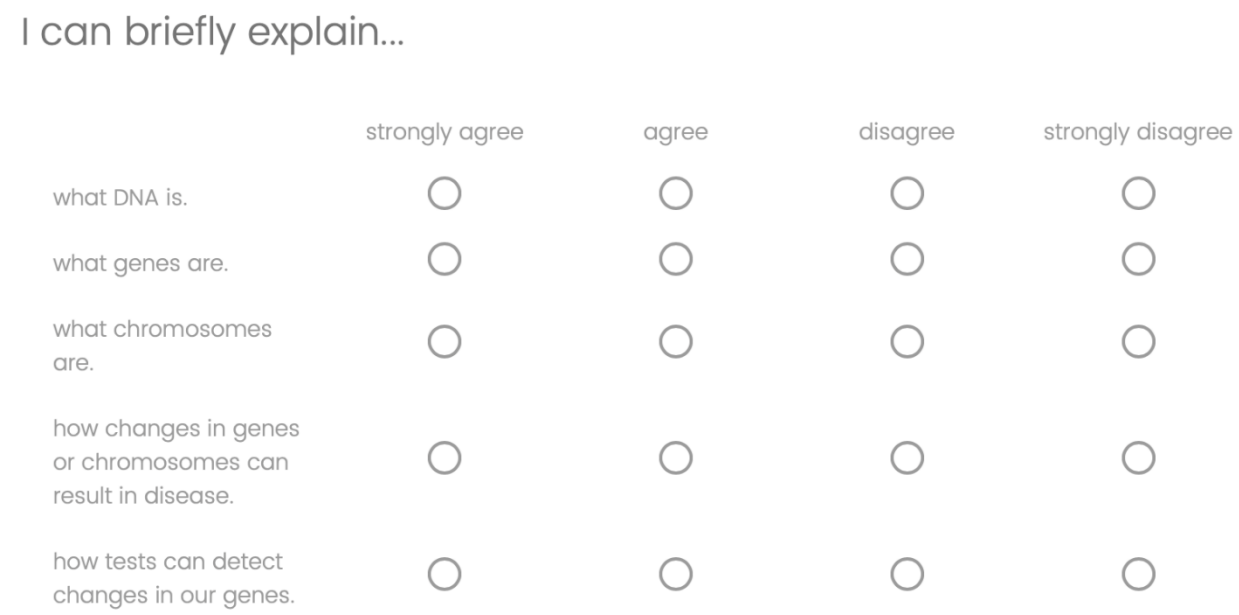
The survey's first question asked participants in which language they are most comfortable communicating (i.e., native language). Subsequently, branch logic was used to display the survey in their language of choice. Next, participants were asked two qualifying questions, "Do you currently live in the United States?" and "Are you at least 18 years old?". Participants who did not answer yes to both questions were informed that they were ineligible to participate and were provided with a link to participate in the raffle. Participants who answered yes to both qualifiers were presented the UCI IRB-approved study information sheet (Appendix D) and asked if they consented to begin the survey.

Figure 1: Survey Design



The survey questions were divided into five sections. Section one collected demographic information and consisted of 10 questions. Section two collected knowledge of basic biology and genetics concepts and consisted of five questions in a matrix table. The English version is displayed in Figure 2.

Figure 2: Section Two - Understanding of Basic Biology and Genetic Concepts Questions



Two questions, shown in Table 1, were embedded with branch logic to enable participants to elaborate further on their responses, if applicable. In section three, participants were asked, “Have you ever heard of a healthcare provider called a genetic counselor?”. The question was embedded with branch logic, and participants who had heard of a genetic counselor were subsequently asked, “Have you ever received genetic counseling services?” After section three, all participants were shown the following statement, “Genetic counselors are health care providers who can help you understand

genetic conditions that could affect your health and your family's health, such as your children or future children."

Table 1: Branch Questions

Question	Answer	Branch
Are you covered by health insurance?	Yes	I have: A: a plan purchased through an employer or union B: a private nongovernmental plan C: a government-provided insurance plan D: Military related health care E: plan through Indian Health Service
	No	proceed to next section
Have you ever heard of a healthcare provider called a genetic counselor?	Yes	Have you ever received genetic counseling services?
	No	proceed to next section

Section four, presented in Table 2, assessed participants' understanding of genetic counseling through 10 true or false statements. Section five, presented in Table 3, assessed attitudes towards genetic counseling through 10 four-point Likert scale questions. Participants answered all 36 questions, watched a video (educational intervention), then re-answered sections two, four, and five again to measure the impact of the video on participants' understanding and attitudes.

Table 2: Section Four - Understanding of Genetic Counseling Questions

Question	Correct Answer
Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic	False
Genetic counseling is available to people who are planning to become pregnant.	True
When someone has an illness (like cancer), genetic test results can help their doctors choose an appropriate treatment.	True
When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy).	False
Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence.	False
You can see a Genetic Counselor even if no one in your family has ever had a genetic (inherited) condition.	True
Genetic counseling is only available to women who are pregnant.	False
Genetic Counselors can change a person's genetic makeup.	False
People who are adopted or have limited information about their blood relatives can benefit from genetic counseling.	True
People who are not interested in genetic testing can still benefit from talking to a genetic counselor.	True

Table 3: Section Five – Attitudes Regarding Genetic Counseling Questions

Statement
I am afraid of my child or myself receiving a genetic diagnosis from a Genetic Counselor.
I know how to get connected with a Genetic Counselor.
I am confident that my conversations with my Genetic Counselor will be kept private. (Including from my employer, health insurance company, and other family members who see the same provider.)
I believe that Genetic Counseling can benefit at least one of my blood family members (parents, siblings, grandparents, aunts, uncles, and/or cousins)
Genetic counseling is something that I <u>can</u> afford.
It is important to me that my genetic counselor has a similar cultural identity as me. (race/identity)
I feel only genetic counselors who share my race or ethnicity can fully understand the cultural undertones behind some of my decisions.
I believe genetic counselors who share my race or ethnicity can facilitate a more inclusive experience for me.
It is important to me that my genetic counselor can speak the same language as me without the use of a translator.
I think I would feel comfortable making a decision about genetic testing after speaking with a Genetic Counselor.

The survey was created in English and translated into Spanish and Vietnamese by native speakers. To ensure uniformity across languages, translated surveys were back translated to English by a native speaker unfamiliar with the study or survey. The survey was translated from English to Spanish by Alex Palacios, LCGC, and back translated to English by Erika Peratoner, second year medical student in the Medical Education Program for the Latino Community at UCI.

The survey was translated from English to Vietnamese by Bao Tran, UCI research assistant, and back translated to English by Leena Tran, LCGC. Dr. Fabiola Quintero-Rivera

reviewed all the Spanish materials. The surveys in English, Vietnamese, and Spanish, and the Vietnamese and Spanish back translations are all listed in Appendices E and F.

2.5 Educational Video Design

In section one of the survey, participants are asked to describe their racial and ethnic identities. The ethno-racial categories were chosen per the 2019 National Institute of Health's (NIH) diversity statement (U.S. Department of Health and Human Services, 2019). Embedded branch logic was used to randomly assign participants to an educational video delivered by a racially and/or linguistically concordant provider or a White provider to compare post-video intervention survey responses between concordantly paired versus non-concordantly paired participants. Spanish-speaking and Vietnamese-speaking participants were randomly assigned to a video delivered in their native language by a native speaker or in English by a White provider with subtitles in their native language. English-speaking participants who indicated they identify as Asian, Black, or Hispanic/Latino/a were either shown a video delivered by an Asian, Black, or Hispanic/Latino/a provider, respectively, or one delivered by a White provider (Figure 3).

For those participants who identified as American Indian or Alaska Native, Middle Eastern or North African, Native Hawaiian or Pacific Islander, or White), the study design was unable to assess the benefits of racial and linguistic provider concordance. However, these participants still had the opportunity to participate in the study and benefit from the educational intervention. They were randomly assigned one of the four English videos delivered by an Asian, Black, Hispanic/Latino, or White provider.

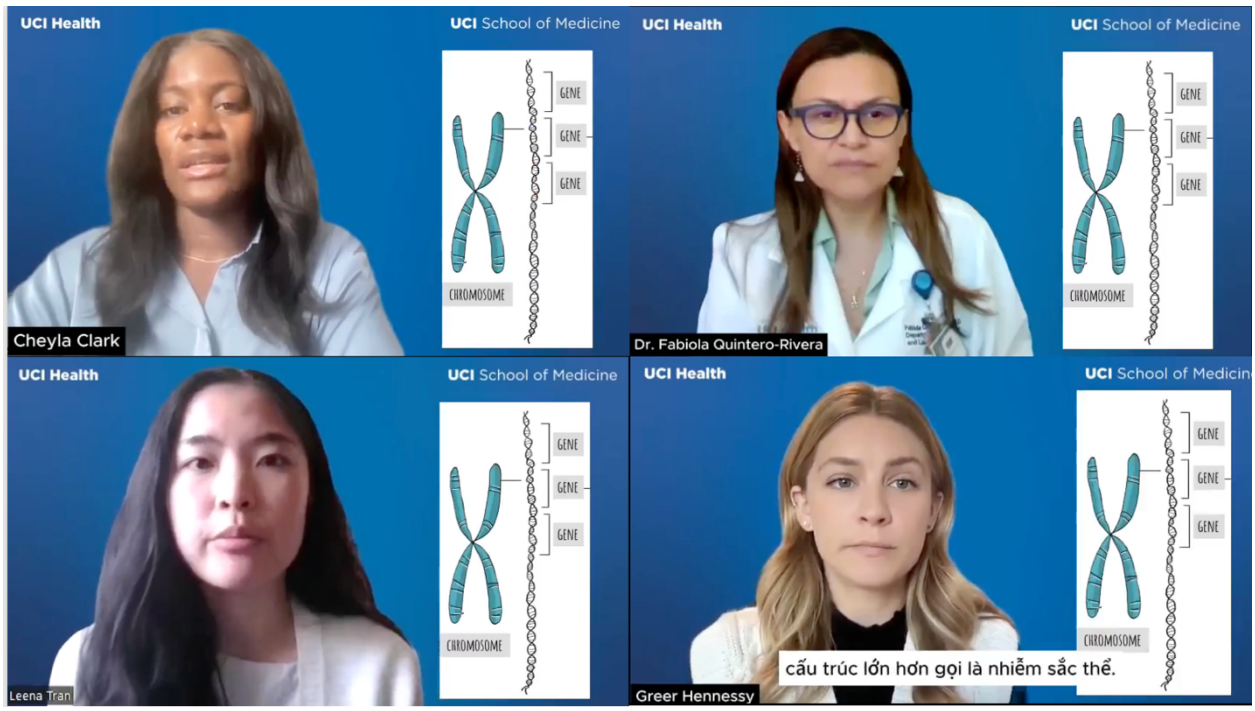
Eight short videos, ranging from five to nine minutes in length, were created using CapCut software (Figure 3). All videos explained the same information about genetics and genetic counseling. The videos provided the information necessary to correctly answer all questions in sections two, four, and five of the post-video survey. Four videos were in English, two were in Spanish, and two were in Vietnamese. English videos were delivered by Leena Tran, LCGC, Dr. Fabiola Quintero-Rivera, MD, Cheyla Clark, CGC, and Greer Hennessy, second-year genetic counseling master's student. The research team wrote a script in English to ensure consistency in content across videos (Appendix G). The providers who delivered the English videos were given the survey questions and the video script and instructed to deliver the same information in the same order. They were instructed not to make changes to the content but encouraged to make stylistic changes, including word order, to better align with their natural speaking style, in an attempt to preserve some of the cultural nuances that can be noticed when listening to a member of a shared cultural, ethnic, or racial group speak.

The Spanish and Vietnamese videos were labeled "*Interpreter video*" or "*Native Speaker video*." For each language, the interpreter video comprised of English videos delivered by the White provider with subtitles in the appropriate language. The native speaker videos were delivered by licensed genetics professionals who were native speakers of either Spanish or Vietnamese to emulate the experience of seeing a provider who can speak one's native language without the utilization of a language interpreter.

For the Spanish videos, Alex Palacios, LCGC, and Dr. Fabiola Quintero-Rivera, MD, provided translations, and Dr. Quintero-Rivera edited the final video subtitles. For the

Vietnamese videos, Leena Tran, LCGC, provided translations, and research assistant Bao Tran edited the final video subtitles.

Figure 3: Educational Videos



2.6 Participants

Individuals 18 or older who could read in English, Spanish, or Vietnamese and currently live in the United States were eligible to participate in the study. Participants did not need United States citizenship to be eligible for the study. All materials were available in English, Spanish, and Vietnamese, and speakers of these languages were targeted for recruitment. These languages were chosen because English, Spanish, and Vietnamese are the first, second, and third most commonly spoken languages in Orange County, California, respectively.

2.7 Protection of Participant Privacy

Study participants were asked to complete an anonymous online survey accessed by an online link through a computer or mobile device. Participants' responses were protected throughout the entire data collection process. Data was stored securely, through password and Duo verification, and confidentially on the lead researcher's private UCI Qualtrics account. Data without identifiers was also stored electronically on the lead researcher's computer. Data was password-protected and maintained in an encrypted format upon completion of the study. Email addresses collected for the gift card drawing were stored separately from the survey responses and were destroyed after compensation distribution.

2.8 Data Management

The initial dataset was evaluated to ensure the responses were valid (Figure 4). When the dataset was downloaded from Qualtrics on April 12, 2024, there were 4,187 recorded responses to the survey. Response reCAPTCHA scores were evaluated. Qualtrics ReCAPTCHA assigns each response a score with values ranging from 0.0 to 1.0. The score 1.0 indicates that the response is very likely legitimate, whereas 0.0 indicates that the response is likely fraudulent, i.e., a bot. Qualtrics uses 0.5 as the cutoff for bot detection. 3,210 responses were removed because they had a reCAPTCHA score of less than 0.5. An additional 95 responses were removed because they did not meet the inclusion criteria of currently living in the United States (n=19), being at least 18 years old (n=45), and/or because they did not choose to indicate their consent to continue (n=31). After removing the likely fraudulent responses and ineligible participants from the dataset, a cohort of 882 responses remained.

Analysis was restricted to only participants who completed at least all of the demographic questions. A cohort of 808 English responses, 20 Spanish responses, and 36 Vietnamese responses remained, totaling 864 responses. Despite recruitment materials being predominantly distributed in Spanish and Vietnamese, of the 864 participants, 95% were English-speaking, 93% were born in the United States, 82% identified as White, 93% had an annual household income of $50,000 or more, and 68% had at least a college education. Participation of bots was highly suspected and, as a further measure to eliminate these illegitimate responses, the cohort was sorted by Latitude and Longitude as recorded by Qualtrics. 28 responses were removed as they were from latitudes and longitudes outside of 18-72°N and 66-178°W, the parameters of the United States. A cohort of 836 responses remained.

The demographic characteristics of the 836 participants are displayed in Appendix H. However, upon initial data analysis, the researchers noticed responses in the White cohort that they highly suspected were indicative of illegitimate responses. These included comparisons between answers to similar or related questions. One example of these incongruent responses is provided in Table 4, which illustrates the responses of White participants to three questions. Participants who answered disagree or strongly disagree to the statement, “I can briefly explain what genes are,” were not expected to answer agree or strongly agree to “I can briefly explain how changes in genes or chromosomes can result in disease,” and/or “I can briefly explain how tests can detect changes in our genes,” as these concepts are more complex and require an understanding of genes to explain. However, more than half of the White participants, highlighted in yellow in Table 4, who agreed or strongly agreed to the second and/or third statements had disagreed or strongly disagreed

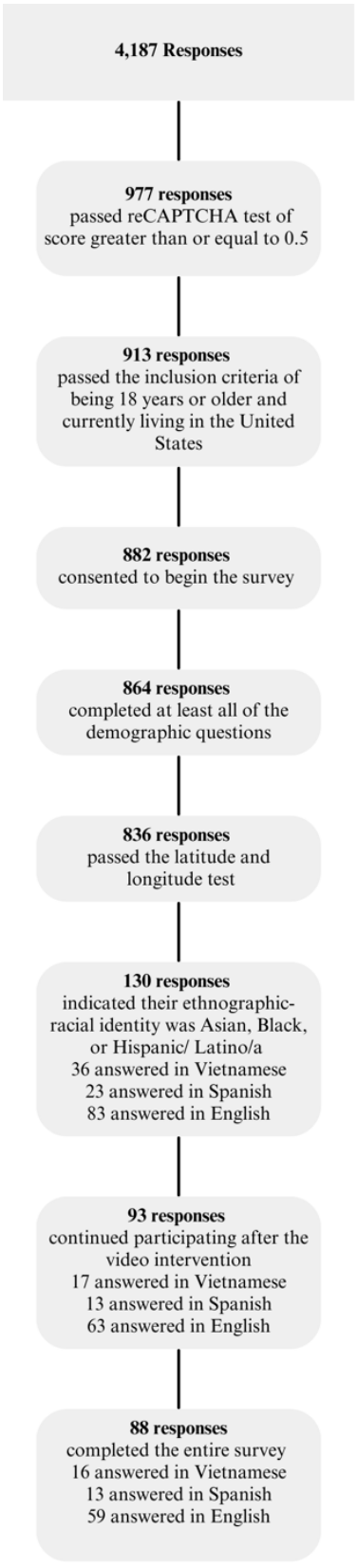
that they could explain what genes are. Based on incongruent findings like these, the research team elected to focus analysis on only participants who were part of the three target Race and Ethnicity groups: Asian, Black or African American, and Hispanic/Latino. A final cohort of 130 participants remained.

Table 4: Incongruent Responses from White Participants Displayed in Yellow Cells

		I can briefly explain how changes in genes or chromosomes can result in disease.		I can briefly explain how tests can detect changes in our genes.	
		Agree/ Strongly Agree	Disagree/ Strongly Disagree	Agree/ Strongly Agree	Disagree/ Strongly Disagree
I can briefly explain what genes are.	Agree/ Strongly Agree	167 (48.5%)	152 (47%)	167 (48.5%)	154 (47.5%)
	Disagree/ Strongly Disagree	177 (51.5%)	172 (53%)	177 (51.5%)	170 (52.5%)

Several variables were consolidated to increase statistical power. For variables with responses that ranged on a 4-point Likert scale from strongly agree to strongly disagree, responses were recoded to a variable that grouped agree and strongly agree into one category and disagree and strongly disagree into a second category. For true and false questions, participants could answer "true," "false," or "I don't know." These were recoded into two categories: "correct" and "not correct," which included "I don't know" or an incorrect response.

Figure 4: Data Management



2.9 Data Analysis

The lead researcher used the IBM Statistical Package for the Social Sciences (SPSS) Statistics version 29 to run the statistical data analyses. Descriptive statistics were used for demographic information. Univariate analysis to compare categorical variables between subgroups was performed using a One-Way ANOVA and Pearson's chi-square test, and Fisher's Exact test was performed when subgroup N<5. McNemar test was used for paired analysis of responses to each question pre-and post-intervention. Nominal p-values are reported with no correction for multiple comparisons. A p-value of less than 0.05 was considered statistically significant. Faculty member, Pamela Flodman, LCGC, MS Applied Statistics, aided in and reviewed data analysis.

2.10 Positionality Statement

There are four authors involved in this study. G.H. identifies as a privileged, educated, White, second-generation American whose ancestors arrived on this continent as immigrants in the mid-20th century. She does not have lived experience as an immigrant, non-English speaker, or as part of a URM, and she acknowledges that this limits the scope of her perspectives in relation to this project. M.B. identifies as a privileged, educated, middle-class White woman whose ancestors arrived on this continent in the late 19th century. In her role as a clinical genetic counselor, she works with patients who speak many languages and have varied cultural backgrounds. A.V. identifies as a privileged, educated, immigrant of South Asian origin. She has experience counseling patients from many cultures who speak many languages and she herself is bilingual in both English and Tamil. F.Q-R. identifies as a first-generation, Medical Doctor and Laboratory Medical

Geneticist and scientist, Latina-American born and raised in Colombia, who is bilingual in both English and Spanish, and through access to superior education has achieved social upward mobility.

III. Results

3.1 Demographics

Of this cohort of 130 participants, 64% (n=83) selected English as their preferred language, 12% (n=16) chose Spanish as their preferred language, and 24% (n=31) chose Vietnamese as their preferred language. 46% (n=60) of participants indicated Asian as their race or ethnicity, 32% (n=42) indicated Black or African American, and 22% (n=28) indicated Hispanic/Latino/a. Most participants were female (72%, n=94), younger than 40 (71%, n=92), born in the United States (57%, n=74), had at least a college degree (65%, n=84), had a religious affiliation (85%, n=110), had health insurance (91%, n=119), and had an income corresponding to middle class ($50,000-$149,999) or above (48%, n=74). The remaining categories are listed in Table 5.

Table 5: Demographics of Participants Analyzed

Preferred Language	**N**	**%**
English	83	64%
Spanish	16	12%
Vietnamese	31	24%
Gender Identity	**N**	**%**
Female	94	72%
Gender-Queer	1	0.8%
Male	31	24%
Non-Binary	3	2%
Transgender	1	0.8%
Age	**N**	**%**
Younger than 30	66	51%
30-39	26	20%
40-49	19	15%
50-59	10	8%
60-69	7	5%

70 or older	2	1%
Self-identified Race or Ethnicity	**N**	**%**
Asian	60	46%
Black or African American	42	32%
HispanicHispanic/Latino	28	28%
Birthplace	**N**	**%**
Born in the United States	74	57%
Born outside of the United States	56	43%
Highest Level of Education Received	**N**	**%**
Elementary (up to grade 8) or less	1	0.8%
High school graduate or GED or less	8	6%
Some College or technical school	37	29%
College graduate	61	47%
Graduate degree	23	18%
Annual Household Income	**N**	**%**
$19,999 or less	14	11%
$20,000- $49,999	30	23%
$50,000 -$99,999	38	29%
$100,000-$149,999	25	19%
$150,000 or more	11	9%
I prefer not to answer	12	9%
Religious Affiliation	**N**	**%**
Buddhist	39	30%
Christian	51	39%
Hindu	1	0.8%
Jewish	1	0.8%
Muslim	3	0.8%
More than one affiliation	15	12%
No affiliation	20	15%
Insurance Coverage	**N**	**%**
No health insurance	11	9%
A plan through Indian Health Service	1	0.8%
Government-provided insurance plan	27	21%
Military related health care	3	2%
Plan purchased through an employer or union	75	57%
Private nongovernmental plan	14	11%

When analyzing education, categories were recoded into *less than a college education*, which comprised of elementary, high school graduate or GED, and some college or technical school, and *college degree or higher*, which included college graduate and graduate degree. For income, responses were recoded into *less than $50,000*, which included $19,999 or less and $20,000-$49,999, and *$50,000 or more*, which combined responses from the $50,000 -$99,999, $100,000-149,999, and $150,000 or more groups. Traditionally, income can be divided into three categories: lower class: less than $52,000; middle class: $52,000-$156,000; and upper class: greater than $156,000. However, as the American middle class has shrunk in the past 50 years, the study team elected to combine the middle and upper classes into one category for data analysis (World Economic Forum, 2022).

There was a positive correlation between higher education and higher income (Pearson's Chi Square test p=0.008), so the study team elected to use only education level for comparisons. There was not a statistically significant difference in education level by race and ethnicity (Pearson's Chi Square test p=0.181). There was a statistically significant difference in education when compared by preferred language (Pearson's Chi Square test p=0.010), with 72% (n=60) of English-speaking participants, 69% (n=11) of Spanish-speaking participants, and 42% (n=13) of Vietnamese-speaking participants having a college degree or higher.

Participants were asked to report the zip code of their primary residence. 64 participants provided zip codes, and 66 declined to respond to this question. Reported zip codes ranged across 12 different states. California was the most reported state; 50% (n=32) of participants reported zip codes in California, the majority of which were located

in Orange County, California (n=30). 74% of Asian participants and 77% of Vietnamese-speaking participants were from California. 42% of Hispanic/Latino participants and 50% of Spanish-speaking participants were from California. Ohio was the second most reported state overall, with 16% (n=10) of participants reporting zip codes within the state. 50% (n=21) of Black or African American participants were from Georgia.

3.2 Pre-Intervention Awareness of Genetic Counseling:

More than half of participants, 57% (n=74) had heard of a healthcare provider called a genetic counselor. However, most participants, 81% (n=105) had never received genetic counseling services. Vietnamese speakers (68%, n=21) and those who had less education than a college degree (54%, n=25) were most likely to be unfamiliar with genetic counseling. The remaining frequencies are listed in Tables 6, 7, and 8.

Table 6: Pre-Intervention Awareness of Genetic Counseling by Preferred Language

Preferred Language	Unfamiliar with genetic counseling	Familiar with genetic counseling but have never received	Familiar with genetic counseling and have received	Total n
English	*31 (37%)*	*34 (41%)*	*18 (22%)*	*83*
Spanish	*4 (25%)*	*6 (38%)*	*6 (38%)*	*16*
Vietnamese	*21 (68%)*	*9 (29%)*	*1 (3%)*	*31*

Table 7: Pre-Intervention Awareness of Genetic Counseling by Race and Ethnicity

Race/Ethnicity	Unfamiliar with genetic counseling	Familiar with genetic counseling but have never received	Familiar with genetic counseling and have received	Total n
Asian	*34 (56.7%)*	*22 (36.7%)*	*4 (6.7%)*	*60*
Black/ African American	*17 (40%)*	*13 (31%)*	*12 (29%)*	*42*
Hispanic/Latino	*5 (18%)*	*14 (50%)*	*9 (32%)*	*28*

Table 8: Pre-Intervention Awareness of Genetic Counseling by Highest Level of Education

Highest Level of Education	Unfamiliar with genetic counseling	Familiar with genetic counseling but have never received	Familiar with genetic counseling and have received	Total n
College Degree or Higher	*31(37%)*	*35 (42%)*	*18 (21%)*	*84*
Less than a College Degree	*25 (54%)*	*14 (31%)*	*7 (15%)*	*46*

3.3 Pre-Intervention Knowledge Assessment: Basic Biology and Genetics

Participants were asked to strongly agree, agree, disagree, or strongly disagree with five statements about their ability to briefly explain basic biology and genetics topics. There was a statically significant difference in rates of agreement by language (Table 9) for the first three statements — *I can briefly explain what DNA is* (Fisher's Exact Test, p=0.046), *I can briefly explain what genes are* (Pearson's Chi Square, p<0.001*), I can briefly explain what chromosomes are (*Fisher's Exact Test, p<0.001) — with Vietnamese speakers having the

lowest rates of agreement. There was not a significant difference by race and ethnicity (Table 10). There was a statistically significant correlation between higher education (college degree or higher) and agreeance to the following three statements: *I can briefly explain what genes are* (Pearson's Chi Square, $p=0.017$), *I can briefly explain what chromosomes are* (Pearson's Chi Square,$p<0.001$), and *I can briefly explain how tests can detect changes in our genes* (Pearson's Chi Square, $p=0.003$). All response rates by education level are shown in Table 11.

Table 9: Pre-Intervention Knowledge Assessment: Basic Biology and Genetics by Preferred Language

	Preferred Language	Agree or Strongly Agree	Disagree or Strongly Disagree	p value
I can briefly explain what DNA is:	*English*	*80 (96%)*	*3 (4%)*	*p=0.046 (fisher)*
	Spanish	*13 (81%)*	*3 (19%)*	
	Vietnamese	*28 (90%)*	*3(10%)*	
I can briefly explain what genes are:	*English*	*82 (99%)*	*1 (1%)*	*p<0.001*
	Spanish	*13(81%)*	*3 (19%)*	
	Vietnamese	*23 (74%)*	*8 (26%)*	
I can briefly explain what chromosomes are:	*English*	*74 (89%)*	*9 (11%)*	*p<0.001 (fisher)*
	Spanish	*10 (62.5%)*	*6 (37.5%)*	
	Vietnamese	*19 (61%)*	*12 (39%)*	
I can briefly explain how changes in our genes can result in disease:	*English*	*66 (80%)*	*17 (20%)*	*p=0.223*
	Spanish	*11 (69%)*	*5 (31%)*	
	Vietnamese	*20 (65%)*	*11 (35%)*	
I can briefly explain how tests can detect changes in our genes:	*English*	*59 (71%)*	*24 (29%)*	*p=0.077*
	Spanish	*10 (62.5%)*	*6 (37.5%)*	
	Vietnamese	*15 (48%)*	*16 (52%)*	

Table 10: Pre-Intervention Knowledge Assessment: Basic Biology and Genetics by Race and Ethnicity

	Race/ Ethnicity	Agree or Strongly Agree	Disagree or Strongly Disagree	p value
I can briefly explain what DNA is:	*Asian*	*56 (93%)*	*4 (7%)*	*p=0.608 (fisher)*
	Black/African American	*40 (95%)*	*2 (5%)*	
	Hispanic/ Latino/a	*25 (89%)*	*3(11%)*	
I can briefly explain what genes are:	*Asian*	*52 (87%)*	*8 (13%)*	*P=0.157 (fisher)*
	Black/African American	*41(98%)*	*1 (2%)*	
	Hispanic/ Latino/a	*25 (89%)*	*3 (11%)*	
I can briefly explain what chromosomes are:	*Asian*	*46 (77%)*	*14 (23%)*	*p=0.194*
	Black/African American	*37 (88%)*	*5 (12%)*	
	Hispanic/ Latino/a	*20 (71%)*	*8 (29%)*	
I can briefly explain how changes in our genes can result in disease:	*Asian*	*45 (75%)*	*15 (25%)*	*p=0.222*
	Black/African American	*30 (71%)*	*12 (29%)*	
	Hispanic/ Latino/a	*22 (79%)*	*6 (21%)*	
I can briefly explain how tests can detect changes in our genes:	*Asian*	*37 (62%)*	*23 (38%)*	*p=0.744*
	Black/African American	*29 (69%)*	*13 (31%)*	
	Hispanic/ Latino/a	*18 (64%)*	*10 (36%)*	

Table 11: Pre-Intervention Knowledge Assessment: Basic Biology and Genetics by Highest Level of Education

	Highest Level of Education	Agree or Strongly Agree	Disagree or Strongly Disagree	p value
I can briefly explain what DNA is:	*College Degree or Higher*	*79 (94%)*	*5 (6%)*	*p=0.347*
	Less than a College Degree	*42 (91%)*	*4 (9%)*	
I can briefly explain what genes are:	*College Degree or Higher*	*80 (95%)*	*4 (5%)*	*p=0.017*
	Less than a College Degree	*38(83%)*	*8 (17%)*	
I can briefly explain what chromosomes are:	*College Degree or Higher*	*74 (88%)*	*10 (12%)*	*p<0.001*
	Less than a College Degree	*29 (63%)*	*17 (37%)*	
I can briefly explain how changes in our genes can result in disease:	*College Degree or Higher*	*67 (80%)*	*17 (20%)*	*p=0.068*
	Less than a College Degree	*30 (65%)*	*16 (35%)*	
I can briefly explain how tests can detect changes in our genes:	*College Degree or Higher*	*62 (74%)*	*22 (26%)*	*p=0.003*
	Less than a College Degree	*22 (48%)*	*24 (52%)*	

3.4 Pre-Intervention Knowledge Assessment: Understanding of Genetics and Genetic Counseling

In this section of the survey, participants were shown 10 statements about genetic counseling and testing (Appendix E) and were asked to indicate if they were true or false. Participants were given a total score from 0-10, with 0 meaning they were unable to

answer any of the questions correctly and 10 being they answered all questions correctly. Overall, there was a statistically significant difference in scores between the three language groups (One-Way ANOVA, p=0.019), with Vietnamese speakers having the lowest average score (4.6) and English and Spanish speakers both having an average score of 6.1. There was a significant difference in scores between the three self-reported ethno-racial groups (One-Way ANOVA, p=0.045); Hispanic/Latino participants had the highest average score of 6.8, compared to 5.3 for Asian participants and 5.6 for Black participants. Between the two education groups, those with a college degree or higher had a significantly higher average score (6.2) than those with less education (4.8) (One-Way ANOVA, p=0.002). Average scores for each group are shown in Table 12.

Table 12: Average Total Scores

Grouped By:	Stratified By:	Mean Score	p value
Language	English	6.1	p=0.019
	Spanish	6.1	
	Vietnamese	4.6	
Race/ Ethnicity	Asian	5.3	p=0.045
	Black	5.6	
	Hispanic/ Latino/a	6.8	
Highest Level of Education	College Degree or Higher	6.2	p=0.002
	Less than a College Degree	4.8	

Of these 10 statements, four common misconceptions were detected across all groups. *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor; When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy); Genetic Counselors help people*

choose desirable traits for their future children such as height, hair color, and intelligence, and *Genetic Counselors can change a person's genetic makeup*, were statements that 40% or more of participants were unable to identify as false (Table 13).

Table 13: Pre-Intervention Common Misconceptions Detected Across All Groups

Statement	Participants unable to identify the statement as false n (%)
Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor.	n=97 (75%)
When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy).	n=89 (69%)
Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence.	n= 67 (52%)
Genetic Counselors can change a person's genetic makeup.	n= 54 (42%)

For these four misconceptions specifically, there was a statistically significant difference for each question between language groups and education groups, but not between ethno-racial groups. These misconceptions were particularly prominent in Vietnamese-speaking participants. For the statement, *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor*, there was a statistically significant difference between language groups (Fisher's Exact Test, p=0.009), with

Vietnamese-speaking participants having the lowest rate of correct answers (7%). Those with a college degree or higher were statistically significantly more likely to get this question correct, (Pearson's Chi Square, $p<0.001$), than those without a college degree. Only 9% of participants with less than a college degree answered this question correctly.

For the statement, *Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence*, there was a statistically significant difference between language groups (Pearson's Chi Square, $p=0.015$), with Vietnamese-speaking participants having the lowest rate of correct answers at 26%. Those with a college degree or higher were statistically significantly more likely to get this question correct (58%), (Pearson's Chi Square, $p=0.002$), than those without a college degree (30%).

For the statement, *Genetic Counselors can change a person's genetic makeup***,** there was a statistically significant difference between language groups (Fisher's Exact Test, $p<0.001$), with Vietnamese-speaking participants having the lowest rate of correct answers at 29%. Those with a college degree or higher were statistically significantly more likely to get this question correct (70%), (Pearson's Chi Square, $p<0.001$), than those without a college degree (37%).

Table 14: Pre-Intervention Common Misconceptions Broken Down by Language, Race/Ethnicity, and Education

Statement	Grouped by	Stratified by	Correct	Not Correct	p value
Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor.	Preferred Language	English	25 (30%)	58 (70%)	p=0.009 (Fisher's)
		Spanish	6 (38%)	10 (62%)	
		Vietnamese	2 (7%)	29 (93%)	
	Race/ Ethnicity	Asian	14 (23%)	46 (77%)	p=0.42
		Black/African American	7 (17%)	35 (83%)	
		Hispanic/ Latino/a	12 (43%)	16 (57%)	
	Highest Level of Education	College Degree or Higher	29 (35%)	55 (65%)	p<0.001
		Less than a College Degree	4 (9%)	42 (91%)	
When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy).	Preferred Language	English	30 (36%)	53 (64%)	p=0.287
		Spanish	3 (19%)	13(81%)	
		Vietnamese	8 (26%)	23 (74%)	
	Race/ Ethnicity	Asian	17 (28%)	43 (72%)	p=0.347
		Black/African American	12 (29%)	30(71%)	
		Hispanic/ Latino/a	12 (43%)	16 (57%)	
	Highest Level of Education	College Degree or Higher	32 (38%)	52 (62%)	p=0.030
		Less than a College Degree	9 (20%)	37 (80%)	
Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence.	Preferred Language	English	46 (55%)	37 (45%)	p=0.015
		Spanish	9 (56%)	7 (44%)	
		Vietnamese	8 (26%)	67 (52%)	

	Race/ Ethnicity	Asian	24 (40%)	36 (60%)	p=0.42
		Black/African American	21 (50%)	21 (50%)	
		Hispanic/ Latino/a	18 (64%)	10 (36%)	
	Highest Level of Education	College Degree or Higher	49 (58%)	35 (42%)	p=0.002
		Less than a College Degree	14 (30%)	32 (70%)	
Genetic Counselors can change a person's genetic makeup.	Preferred Language	English	57 (69%)	26 (31%)	p<0.001
		Spanish	10 (62.5%)	6 (37.5%)	
		Vietnamese	9 (29%)	22 (71%)	
	Race/ Ethnicity	Asian	29 (48%)	31 (52%)	p=0.080
		Black/African American	27 (64%)	15 (36%)	
		Hispanic/ Latino/a	20 (71%)	8 (29%)	
	Highest Level of Education	College Degree or Higher	59 (70%)	25 (30%)	p<0.001
		Less than a College Degree	17 (37%)	29 (63%)	

3.5 Pre-Intervention Attitude Assessment

For this section, participants were shown ten statements (Appendix E) about attitudes relating to genetic counseling. They were asked to indicate if they strongly agreed, agreed, disagreed, or strongly disagreed with the statement. Half of participants (50%, n=65) responded disagree or strongly disagree to the statement, "Genetic counseling is something that I can afford." There was not a statistically significant difference in response to this question across preferred language, ethno-racial identity, income, or insurance type.

Additionally, across all groups, 37% (n=48) agreed or strongly agreed with the statement, *"I am afraid of my child or myself receiving a genetic diagnosis from a Genetic Counselor."*

However, participants responded favorably to the three statements (Table 15) that centered around perceived trust and value of genetic counseling and counselors. 94% (n=119) agreed or strongly agreed that they are confident their conversations with a genetic counselor will be kept private. 89% (n=116) agreed or strongly agreed that genetic counseling can benefit at least one of their blood family members. 92% (n=119) agreed or strongly agreed that they would feel comfortable making a decision about genetic testing after speaking with a genetic counselor. There was no significant difference in responses across preferred language, race and ethnicity, or education.

Table 15: Participants' Pre-Intervention Trust and Value of Genetic Counseling

Statement	Rate of Agree or Strongly Agree Responses n (%)
I am confident that my conversations with my Genetic Counselor will be kept private. (Including from my employer, health insurance company, and other family members who see the same provider.	119 (92%)
I believe that Genetic Counseling can benefit at least one of my blood family members (parents, siblings, grandparents, aunts, uncles, and/or cousins).	116 (89%)
I think I would feel comfortable making a decision about genetic testing after speaking with a Genetic Counselor.	119 (92%)

Four statements targeted preferences for ethno-racially and/or linguistically concordant providers. Responses, shown in Table 16, indicated a high preference for concordant providers. This was true across all groups, as there was not a statistically significant difference across preferred language, race and ethnicity, or education.

Table 16: Participants' Pre-Intervention Preferences for Ethno-racially and Linguistically Concordant Providers

Statement	Rate of Agree or Strongly Agree Responses n (%)
It is important to me that my genetic counselor has a similar cultural identity as me. (race/identity)	82 (63%)
I feel only genetic counselors who share my race or ethnicity can fully understand the cultural undertones behind some of my decisions.	83 (64%)
I believe genetic counselors who share my race or ethnicity can facilitate a more inclusive experience for me.	94 (72%)
It is important to me that my genetic counselor can speak the same language as me without the use of a translator.	109 (84%)

3.6 Post-Intervention Knowledge Assessment: Basic Biology and Genetics

Pre-intervention analysis evaluated the responses of the 130 participants who answered all questions before the video intervention. However, only 88 participants completed the whole survey (Figure 4). Therefore, an N of 88 was used for post-intervention analysis. Their demographic breakdown is shown in Table 17.

Table 17: Demographic Information of 88 Participants who Completed the Full Survey

Preferred Language	**N**	**%**
English	59	67%
Spanish	13	15%
Vietnamese	16	18%
Self-identified Race or Ethnicity	**N**	**%**
Asian	35	40%
Black or African American	33	37%
Hispanic or Latino	20	23%
Highest Level of Education Received	**N**	**%**
Elementary (up to grade 8) or less	0	0%
High school graduate or GED or less	5	6%
Some College or technical school	23	26%
College graduate	42	48%
Graduate degree	18	20%

Table 18: Pre- vs. Post-Intervention Knowledge Assessment: Basic Biology and Genetics

	Agree or Strongly Agree Pre-Intervention	Agree or Strongly Agree Post-Intervention	p value
I can briefly explain what DNA is	79 (90%)	87(98%)	p=0.008
I can briefly explain what genes are	78 (89%)	86(98%)	p=0.021
I can briefly explain what chromosomes are	67 (76%)	83 (94%)	p<0.001
I can briefly explain how changes in our genes can result in disease	65 (74%)	84 (95%)	p<0.001
I can briefly explain how tests can detect changes in our genes	55 (63%)	80 (81%)	p<0.001

Overall, basic biology and genetics knowledge average scores improved significantly for all questions, shown in Table 18. For the first question, I can briefly explain what DNA is, eight (9%) of the 88 participants changed their responses from disagree/strongly

disagree to agree/strongly agree, while zero (0%) changed from agree/strongly agree to disagree/strongly disagree. This indicates that the intervention resulted in a significant increase in the proportion of participants who indicated that they are comfortable explaining what DNA is (McNemar test, p=0.008). Increases could not be significantly detected when compared by preferred language or by race/ethnicity due to the small sample size, but rates by preferred language and ethno-racial identity are displayed in figures 5 and 6, respectively.

Figure 5: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain what DNA is by Preferred Language

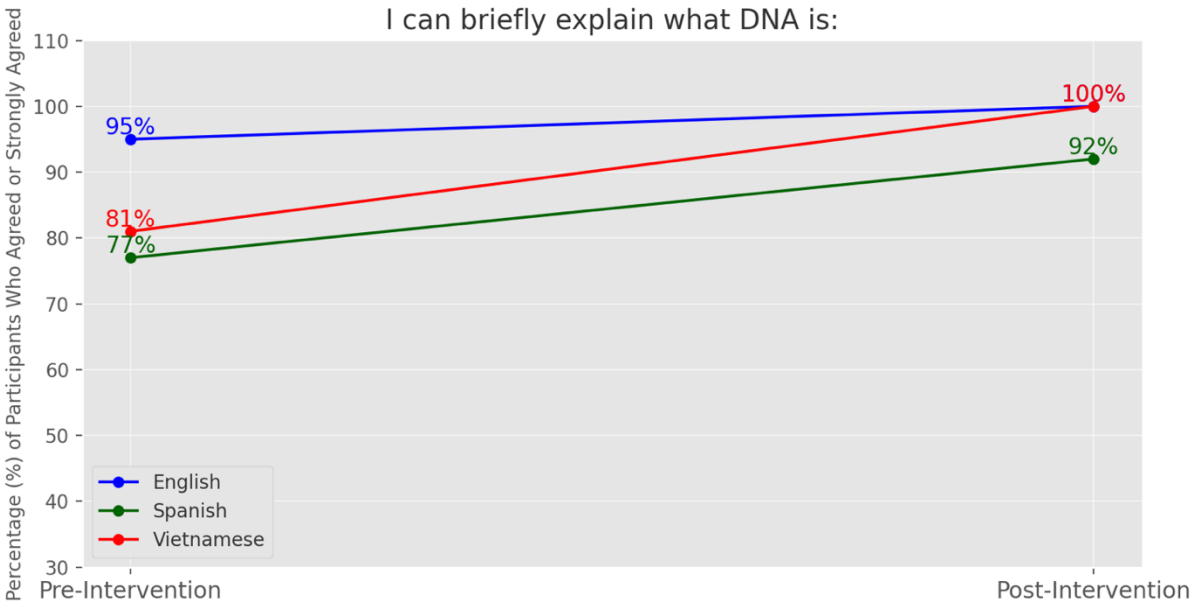
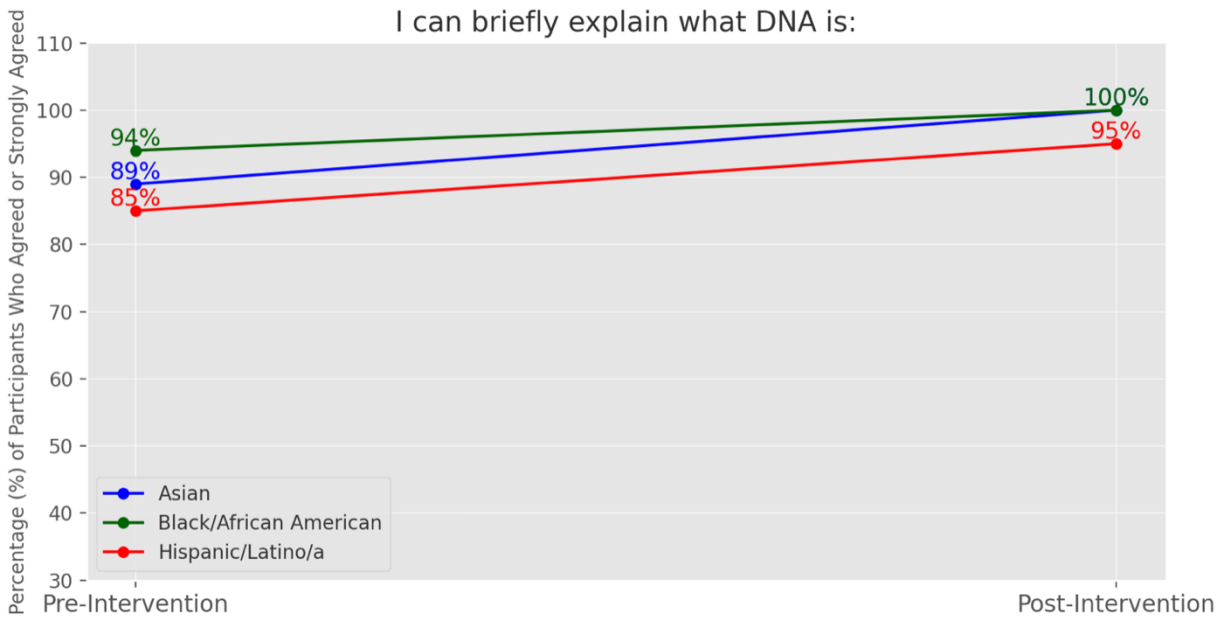


Figure 6: *Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain what DNA is by Race/Ethnicity*



For the second question, *I can briefly explain what genes are*, nine (11%) of the 88 participants changed their responses from disagree/strongly disagree to agree/strongly agree, while one (1%) changed from agree/strongly agree to disagree/strongly disagree. This indicates that the intervention resulted in a significant increase in the proportion of participants who indicated that they are comfortable explaining what genes are (McNemar test, p=0.008). Increases could not be significantly detected when compared by preferred language or by race/ethnicity due to the small sample size, but rates by preferred language and ethno-racial identity are displayed in figures 7 and 8, respectively.

Figure 7: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain what genes are by Preferred Language

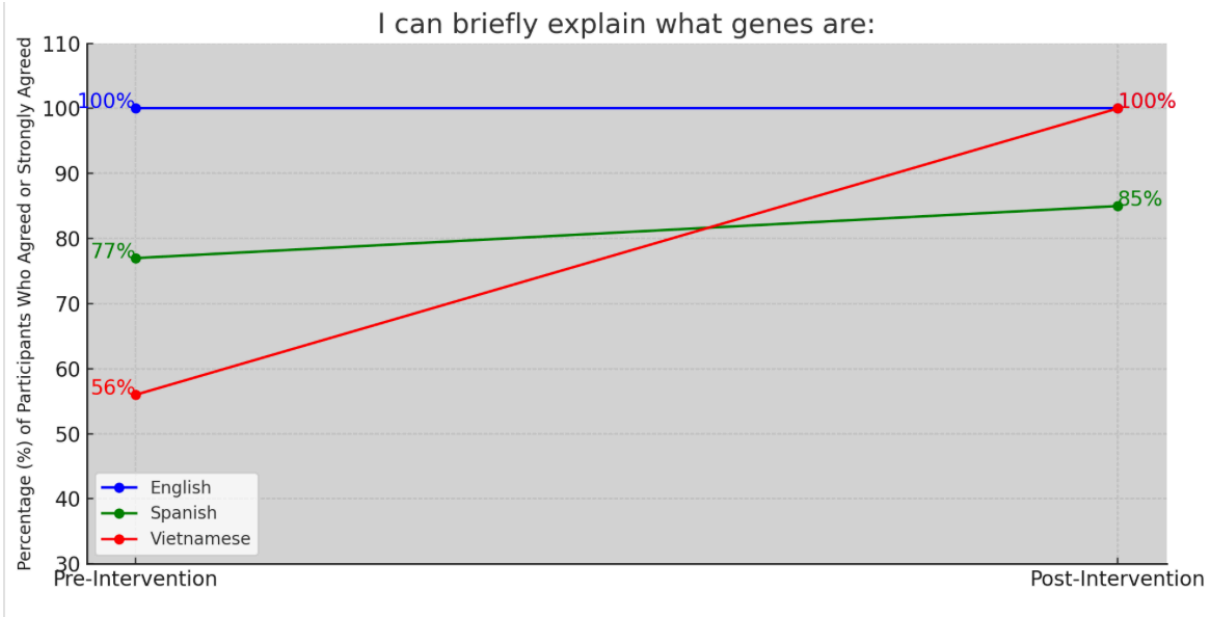
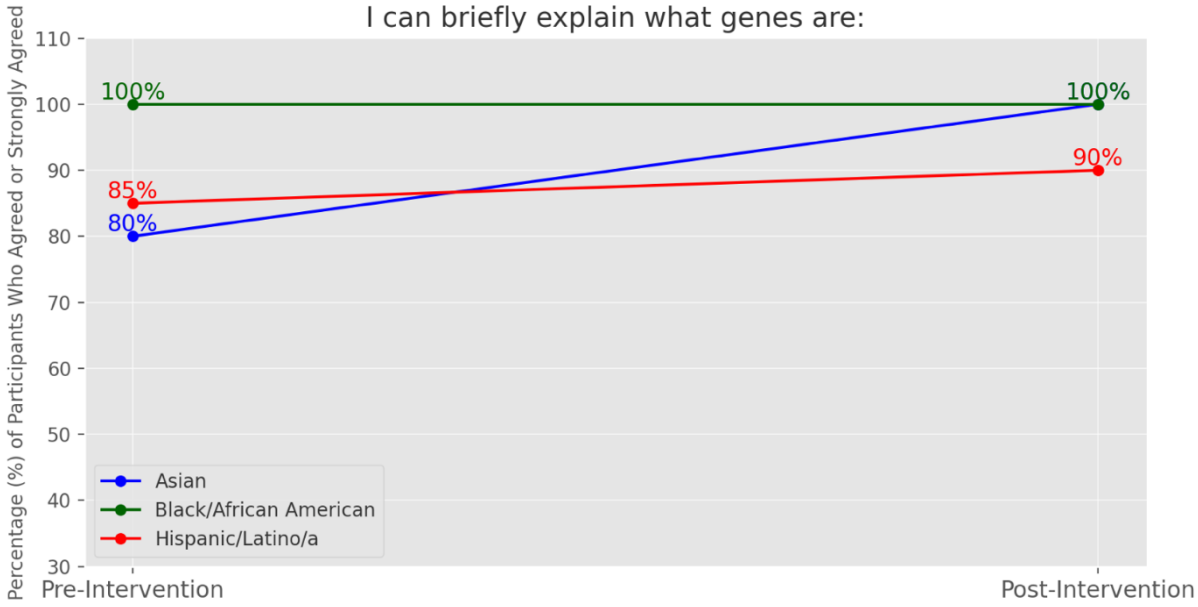


Figure 8: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain what genes are by Race/ Ethnicity



For the third question, *I can briefly explain what chromosomes are*, 17 (19.3%) of the 88 participants changed their responses from disagree/strongly disagree to agree/strongly agree, while one participant (1.1%) changed from agree/strongly agree to disagree/strongly disagree. Overall, there was a significant increase in the proportion of participants who indicated they were comfortable explaining what chromosomes are post-intervention (McNemar test, $p<0.001$). When compared by preferred language, there was a significant increase in reported ability to explain what chromosomes are among English speakers ($p=0.031$) and Vietnamese speakers (McNemar test, $p=0.016$); among Spanish speakers, there was no significant difference post-intervention(McNemar test, $p=0.375$). When compared by self-reported race and ethnicity, there was a significant increase in comfort in explaining what chromosomes are among Asian participants (McNemar test, $p=0.004$) but no significant change post-intervention for Black or Hispanic/Latino participants (McNemar test, $p=0.250$ and $p=0.219$, respectively).

Figure 9: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain what chromosomes are by Preferred Language

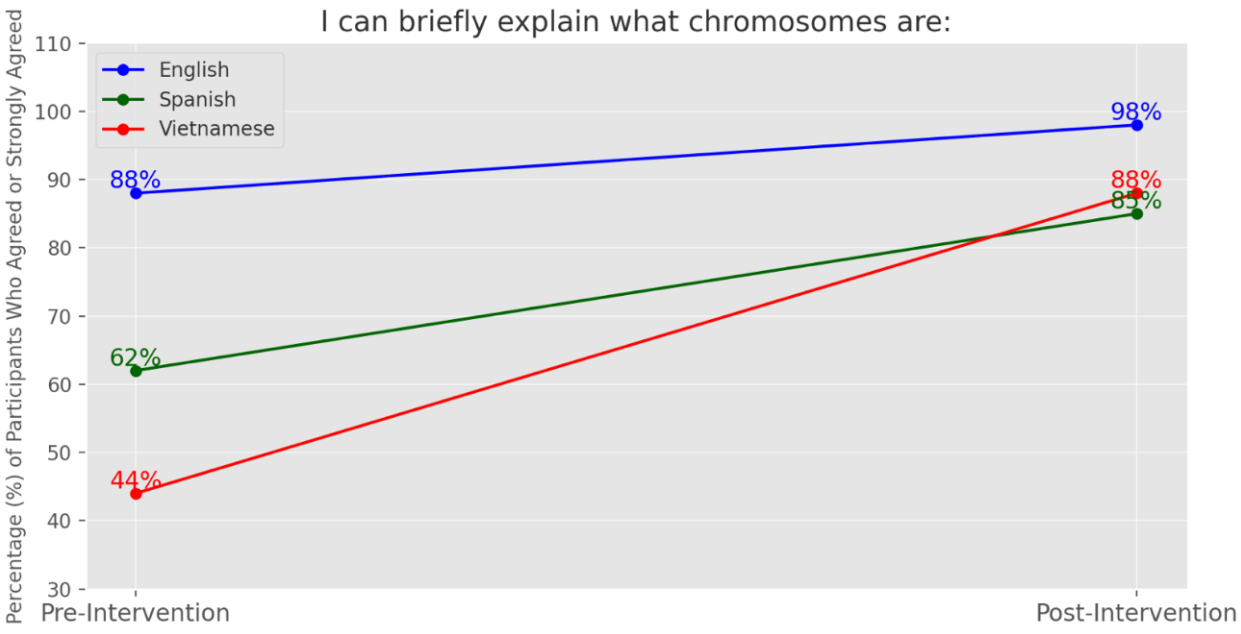
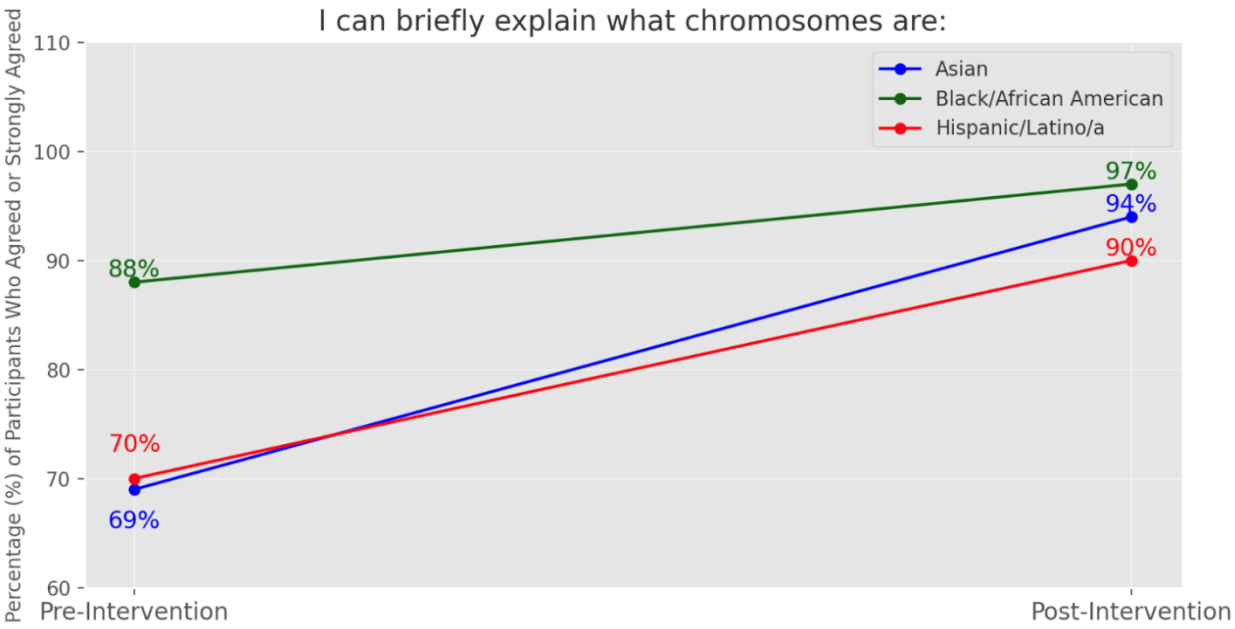


Figure 10: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain what chromosomes are by Race/ Ethnicity



For the fourth question, *I can briefly explain how changes in our genes can result in disease*, 22 (25%) of the 88 participants changed their responses from disagree/strongly disagree to agree/strongly agree, while three participants (3.4%) changed from agree/strongly agree to disagree/strongly disagree. This indicates that the intervention resulted in a significant increase in the proportion of participants who indicated that they are comfortable explaining how changes in genes or chromosomes can result in disease. (McNemar test, p<001). When compared by preferred language, there was a significant increase in reported ability to explain what chromosomes are among English speakers (p= 0.022) and among Vietnamese speakers (McNemar test, p=0.007); among Spanish speakers, there was no significant difference post-intervention (McNemar test, p=0.625).

When compared by self-reported race and ethnicity, there was a significant increase in confidence in explaining what chromosomes are among Asian participants (p=0.022)

and Black participants (McNemar test, p=0.016), but no significant change post-intervention for Hispanic/Latino participants(McNemar test, p=0.375).

Figure 11: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain how changes in our genes can result in disease by Preferred Language

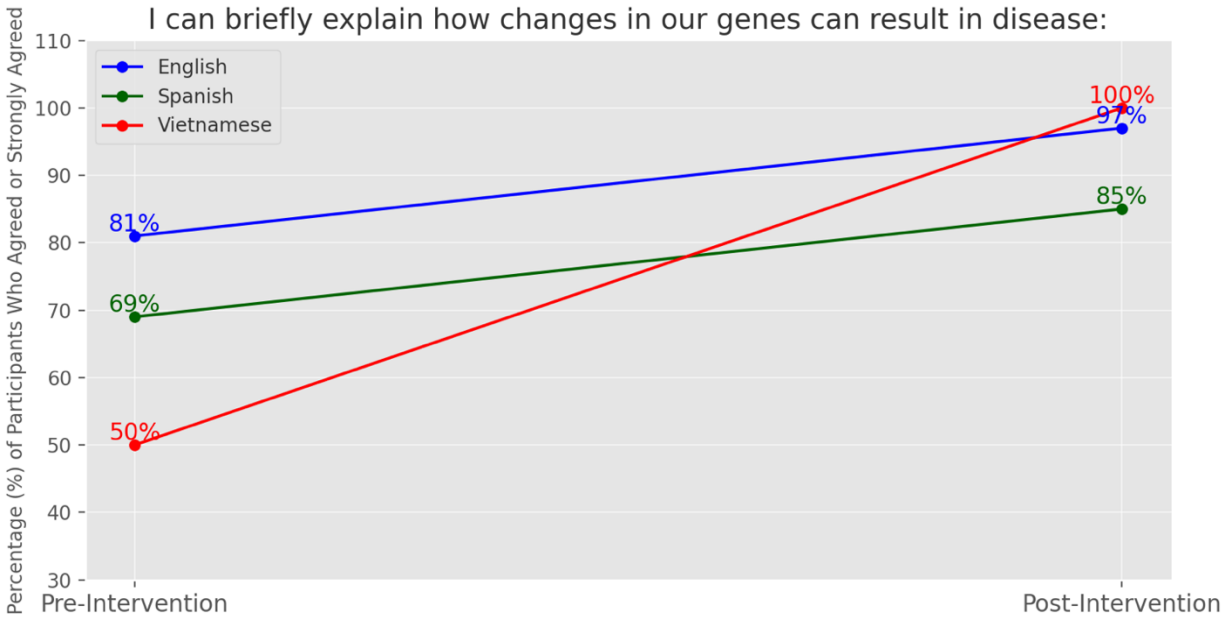
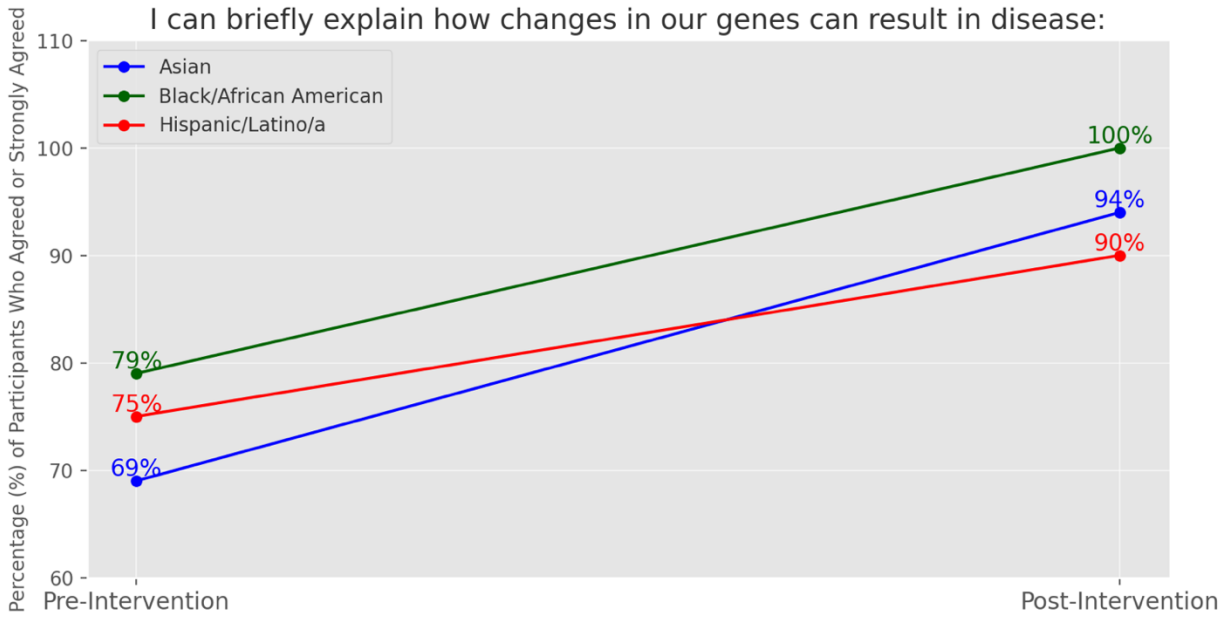


Figure 12: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain how changes in our genes can result in disease by Race/ Ethnicity



For the fifth question, *I can briefly explain how tests can detect changes in our genes*, 26 (30%) of the 88 participants changed their responses from disagree/strongly disagree to agree/strongly agree, while seven participants (8%) changed from agree/strongly agree to disagree/strongly disagree. This indicates that the intervention resulted in a significant increase in the proportion of participants who indicated that they are comfortable explaining how tests can detect changes in our genes (McNemar test, $p<001$). When compared by preferred language, there was a significant increase in reported ability to explain what chromosomes are among English speakers (McNemar test, $p<0.001$) and Vietnamese speakers (McNemar test, $p=0.018$); among Spanish speakers, there was no significant difference post-intervention (McNemar test, $p=0.125$). When compared by self-reported race and ethnicity, there was a significant increase in comfort in explaining what chromosomes are among Asian participants (McNemar test, $p<0.001$) and Hispanic/Latino/a participants (McNemar test, $p=0.031$) but no significant change post-intervention for Black participants (McNemar test, $p=0.070$).

Figure 13: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain how tests can detect changes in our genes by Preferred Language

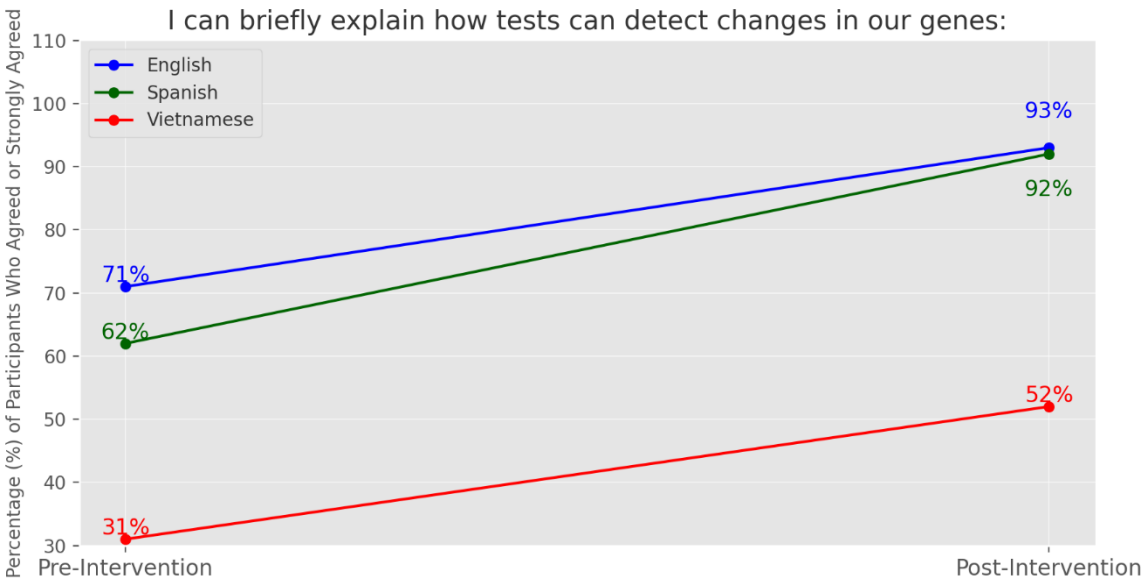
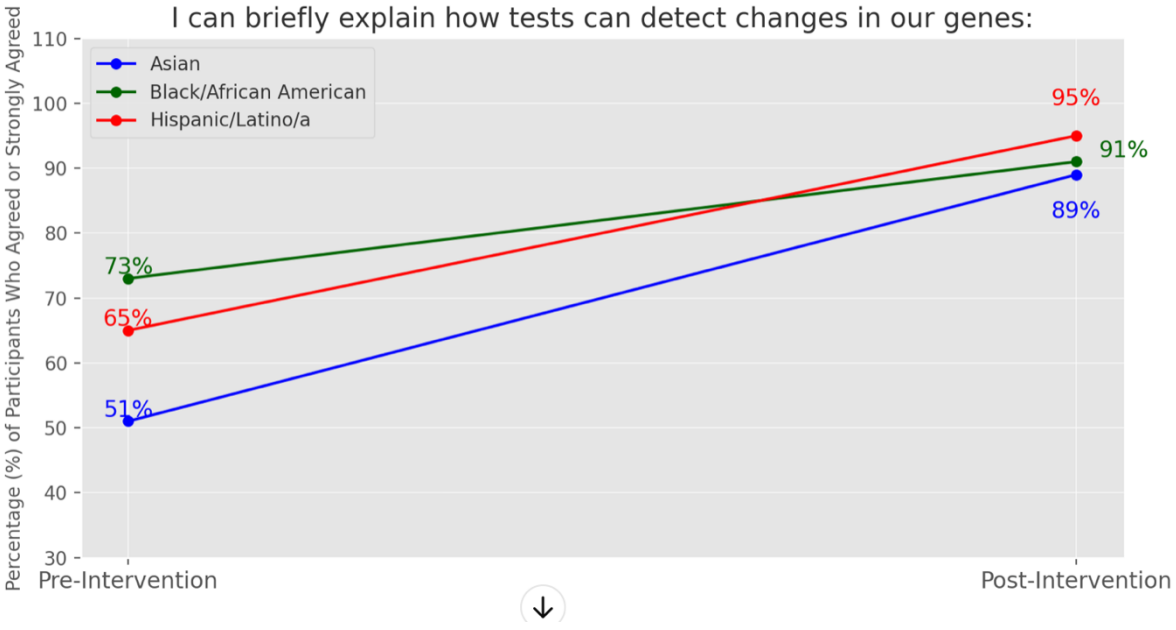


Figure 14: Pre- vs. Post-Intervention Knowledge Assessment: I can briefly explain how tests can detect changes in our genes by Race/Ethnicity



3.7 Post-Intervention Assessment: Understanding of Genetics and Genetic Counseling

When participants re-answered the true or false understanding questions after viewing the educational video intervention, there was a statistically significant increase in correct answers for seven out of the 10 questions (Table 19). Of the seven statements in which there was a statistically significant improvement in scores observed, there was a statistically significant correlation between provider-participant concordance and improved score for six questions (Figure 15): *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor* (McNemar test, p=0.021); *Genetic counseling is available to people who are planning to become pregnant* (McNemar test, p=0.012); *When someone has an illness (like cancer), genetic test results can help their doctors choose an appropriate treatment* (McNemar test, p<0.001); *When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy)* (McNemar test, p=0.045); *You can see a Genetic Counselor even if no one in your family has ever had a genetic (inherited) condition* (McNemar test, p=0.006); and *People who are adopted or have limited information about their blood relatives can benefit from genetic counseling* (McNemar test, p<0.001).

Table 19: Pre- vs. Post-Intervention Knowledge Assessment: Understanding of Genetics and Genetic Counseling

Statement	Correct response Pre-intervention	Correct response post-intervention	Significant Change Post Intervention	Video Concordance Corelated with Significant Improvement
Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor.	24 (27%)	40 (46%)	Yes p=0.002	Yes p=0.021
Genetic counseling is available to people who are planning to become pregnant.	65 (74%)	80 (91%)	Yes p=0.004	Yes p=0.012
When someone has an illness (like cancer), genetic test results can help their doctors choose an appropriate treatment.	59 (67%)	82 (93%)	Yes p<0.001	Yes p<0.001
When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy).	25 (28%)	47 (53%)	Yes p<0.001	Yes 0.035
Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence.	44 (50%)	48 (55%)	No p=0.541	No p=0.227
You can see a Genetic Counselor even if no one in your family has ever had a genetic (inherited) condition.	65 (74%)	84 (96%)	Yes p<0.001	Yes p=0.006

Genetic counseling is only available to women who are pregnant.	62 (71%)	68 (77%)	No p=0.238	No p=1.000
Genetic Counselors can change a person's genetic makeup.	55 (63%)	53 (60%)	No p=0.839	No p=1.000
People who are adopted or have limited information about their blood relatives can benefit from genetic counseling.	57 (65%)	81 (92%)	Yes p<0.001	Yes p<0.001
People who are not interested in genetic testing can still benefit from talking to a genetic counselor.	72 (82%)	84 (96%)	Yes p<0.008	No P=0.070

Figure 15: Statements in which video concordance significantly correlated with improved scores

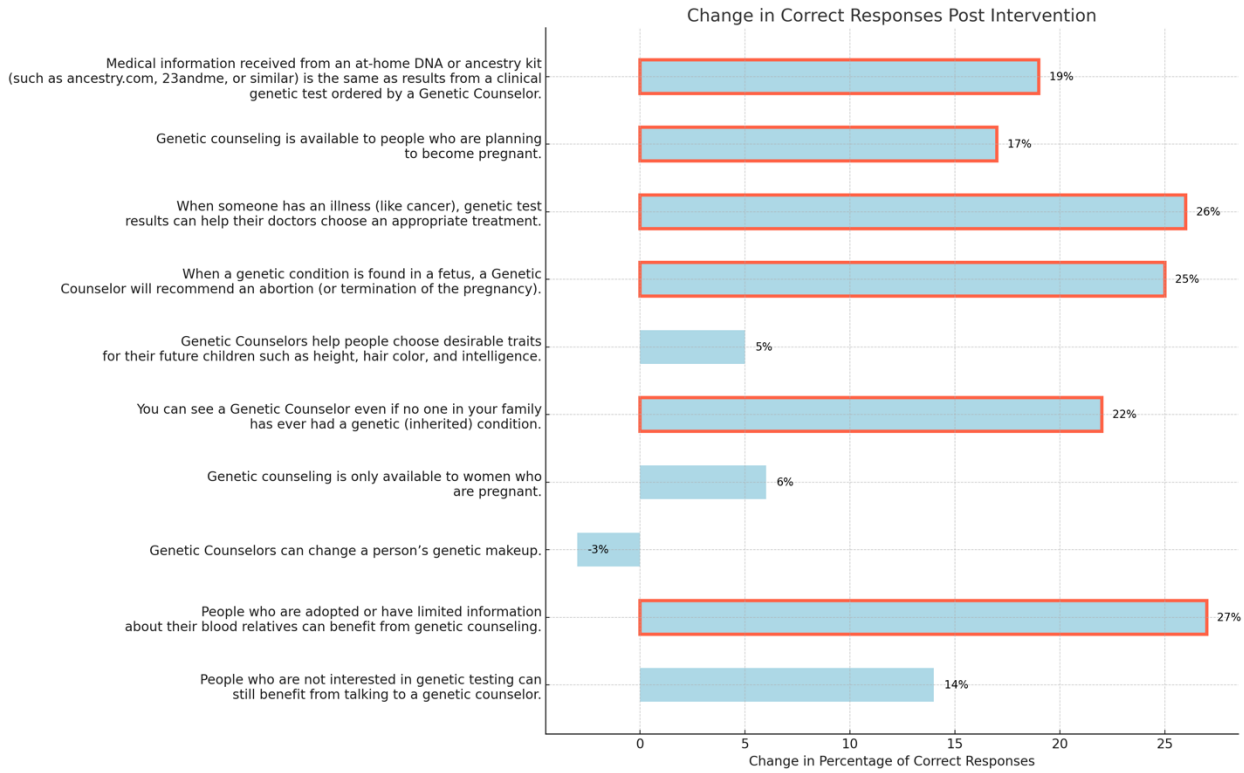


Figure 15 shows the difference in correct response percentages before and after the intervention. The bars outlined in red indicate statements in which video concordance significantly correlated with improved scores.

Of the three statements in which there was not a statistically significant increase in scores, the first had a high correct response rate pre-intervention, and two were from the common misconceptions listed in Table 10. For the statement, *Genetic counseling is only available to women who are pregnant*, the initial score was high, with 71% (n=62) of participants correctly identifying this as a false statement pre-intervention. Of the four common misconceptions listed in Table 10, two statements — *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor* and *When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy* — significantly improved post-intervention (table 20); two statements — *Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence* and *Genetic Counselors can change a person's genetic makeup* — did not demonstrate a significant increase in correct responses between the pre- and post-interventions (table 21).

Table 20: Misconceptions that Improved Post-Intervention

Statement	Grouped by	Stratified by language, or ethno-racial identity	Correct Pre-Intervention	Correct Post-Intervention	p value
Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor.	Preferred Language	English	*18 (36%)*	*29 (49%)*	*p=0.013*
		Spanish	*5 (38%)*	*9 (69%)*	*p=0.125*
		Vietnamese	*1 (6%)*	*2 (13%)*	*p=1.00*
	Race/ Ethnicity	Asian	*9 (26%)*	13 (37%)	*p=0.289*
		Black/African American	*6 (18%)*	*13 (39%)*	*p=0.039*
		Hispanic/ Latino/a	*9 (45%)*	*14 (70%)*	*p=0.125*
When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy).	Preferred Language	English	*20 (34%)*	*34 (58%)*	*p=0.003*
		Spanish	*2 (15%)*	*9 (69%)*	*p=0.016*
		Vietnamese	*3 (19%)*	*4 (25%)*	*p=1.00*
	Race/ Ethnicity	Asian	*8 (23%)*	13 (37%)	*p=0.227*
		Black/African American	*10 (30%)*	*18 (55%)*	*p=0.039*
		Hispanic/ Latino/a	*7 (35%)*	*16 (80%)*	*p=0.004*

For the statement, *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor*, out of 88 responses, 20 (22.7%) changed their answer from an incorrect to a correct answer, while four (4.5%) changed from correct answer to an

incorrect answer. This was a statistically significant increase in the proportion of participants who answered this question correctly (McNemar test, p=0.002). There was a significant correlation between viewing a concordant provider video and improvement in score (McNemar test, p=0.021). When the three language groups were analyzed separately, a significant change was also observed in the English-speaking subgroup (McNemar test, p=0.013). No significant change was detected in the Spanish-speaking (McNemar test, p=0.125) or Vietnamese-speaking subgroups (McNemar test, p=1.000). When the race/ethnicity groups were analyzed separately, a significant change was also seen in the Black subgroup (McNemar test, p=0.039). No significant change was detected in the Asian (McNemar test, p=0.039) or Hispanic/Latino subgroups (McNemar test, p=0.125).

For the statement, *When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy*), out of 88 respondents, 27 (30.7%) changed their answer from an incorrect to a correct answer, while five (5.7%) changed from correct answer to an incorrect answer. This was a statistically significant increase in the proportion of participants who answered this question correctly (McNemar test, p<0.001). When the three language groups were analyzed separately, a significant change was also noted in the English-speaking subgroup (McNemar test, p=0.003) and the Spanish-speaking subgroup (McNemar test, p=0.016). However, no significant change was detected in the Vietnamese-speaking subgroup (McNemar test, p=1.000). When the race/ethnicity groups were analyzed separately, a significant change was also seen in the Black subgroup (McNemar test, p=0.039) and the Hispanic/Latino subgroup (McNemar test, p=0.004). No significant change was detected in the Asian subgroup (McNemar test, p=0.227).

There was not a significant increase in people's ability to detect the statements shown in Table 21, *Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence* (McNemar test, p=0.541) and *Genetic Counselors can change a person's genetic makeup as false* (McNemar test, p=0.839).

Table 21: Misconceptions that Remained Post-Intervention

Statement	Grouped by	Stratified by language, or ethno-racial identity	Correct Pre-Intervention	Correct Post-Intervention	p value
Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence.	Preferred Language	English	33 (56%)	35 (59%)	*p=0.815*
		Spanish	8 (62%)	11 (85%)	*p=0.250*
		Vietnamese	3 (19%)	2 (13%)	*p=1.000*
	Race/ Ethnicity	Asian	*12 (34%)*	12 (34%)	*p=1.000*
		Black/African American	*18 (55%)*	*19 (58%)*	*p=1.000*
		Hispanic/ Latino/a	*14 (70%)*	*17 (85%)*	*p=0.250*
Genetic Counselors can change a person's genetic makeup.	Preferred Language	English	41 (70%)	40 (68%)	*p=1.000*
		Spanish	9 (69%)	9 (69%)	*p=1.000*
		Vietnamese	5 (31%)	4 (25%)	*p=1.000*
	Race/ Ethnicity	Asian	17 (49%)	17 (49%)	*p=1.000*
		Black/African American	22 (67%)	20 (61%)	*p=0.791*
		Hispanic/ Latino/a	16 (80%)	16 (80%)	*p=1.000*

3.8 Post-Intervention Attitude Assessment

Prior to the educational intervention, only 52% (n=46) of participants agreed or strongly agreed that genetic counseling is something that they can afford. Post-intervention, this increased to 81% (n=71). Out of the 88 participants, 25 participants (28.4%) changed from disagree/strongly disagree to agree/strongly agree, while zero (0.0%) changed from agree/strongly agree to disagree/strongly disagree. This indicates that the intervention resulted in a significant increase in the proportion of participants who believed they could afford genetic counseling (McNemar test, $p<0.001$). When the three language groups were analyzed separately, a significant change was noted in the English-speaking subgroup (McNemar test, $p<0.001$) and the Vietnamese-speaking subgroup (McNemar test, $p=0.031$). No significant change was detected in the Spanish-speaking subgroup (McNemar test, $p<0.063$). When the race/ethnicity groups were analyzed separately, a significant change was noted in all three subgroups: Asian (McNemar test, $p<0.002$), Black (McNemar test, $p<0.004$), and Hispanic/Latino/a (McNemar test, $p<0.031$).

Pre-intervention, 37% of participants agreed or strongly agreed that they were afraid of their child or themself receiving a genetic diagnosis from a genetic counselor. There was no statistically significant increase in this rate (McNemar test, $p=0.424$), indicating that this fear was not ameliorated by obtaining more information about genetic counseling and testing.

There was not a statistically significant increase in preference for concordant providers after the intervention, as displayed in Table 18. However, the majority of participants across all groups agreed or strongly agreed with all of the following statements listed in Table 22 pre- and post-intervention.

Table 22: Preferences for Ethno-Racially and Linguistically Concordant Providers Post-Intervention

Statement	Agree/ Strongly Agree Pre-Intervention	Agree/ Strongly Agree Post-Intervention	p value
It is important to me that my genetic counselor has a similar cultural identity as me. (race/identity)	56 (64%)	61 (69%)	p=0.302
I feel only genetic counselors who share my race or ethnicity can fully understand the cultural undertones behind some of my decisions.	58 (66%)	55 (63%)	p=0.607
I believe genetic counselors who share my race or ethnicity can facilitate a more inclusive experience for me.	63 (72%)	63 (72%)	p=1.000
It is important to me that my genetic counselor can speak the same language as me without the use of a translator.	75 (85%)	78 (89%)	p=0.508

IV. Discussion

It has been well established that disparities have historically existed and persist within the healthcare system (Anderson, 2012; Cooper et al., 2012; Hagiwara et al., 2023; Lowe et al., 2020; Matalon et al., 2023; Schaa et al., 2015). Ensuring culturally competent care from all healthcare providers is crucial. However, the low percentage (13%) of non-White genetic counselors highlights the need for diverse providers to improve care for marginalized/URM groups (NSGC, 2024). The critical nature of this issue is reflected by the National Human Genome Research Institute's priority to diversify the genetics workforce to reduce medical mistrust and clinician bias and enhance culturally competent care and research opportunities (Bonham et al., 2021; Quintero-Rivera et al., 2020). Thus, the present study aimed to address the following research questions: what are existing attitudes or disparities in knowledge about genetic counseling in members of URM groups that may be acting as barriers to accessing care; do URMs have a preference for ethno-racially and/or linguistically concordant genetics providers; and does information delivered by a concordant provider versus by a non-concordant provider have an ability to change URMs' knowledge levels and attitudes about genetic testing and counseling?

4.1 Awareness of and Exposure to Genetic Counseling

Spanish-speaking participants were most likely to have heard of genetic counseling (76%), followed by English-speaking participants (63%). Vietnamese-speaking participants (32%) were less likely to have heard of genetic counseling than English or Spanish speakers. Similarly, 38% of Spanish-speaking participants and 22% of English-speaking

participants had received genetic counseling, compared to only 3% of Vietnamese-speaking participants (table 6). Hispanic/Latino participants, including both English and Spanish speakers, were the group most likely to have heard of genetic counseling (82%) (table 7).

It is unlikely that these rates indicate that awareness of genetic counseling is truly higher in Hispanic/Latino-American communities than in other under-represented communities. In previous studies, Hispanic/Latino individuals displayed lower awareness and knowledge of genetic counseling topics than their non-Hispanic White counterparts (Canedo et al., 2018; Hillyer, 2020; Singer et al., 2004). It is possible these results instead indicate that Hispanic/Latino participants are more likely to engage with genetics research when they are already familiar with medical genetics topics. Conversely, of people who are unfamiliar with genetic counseling, Hispanic/Latino people may be less likely to engage in this type of research. Additionally, Hispanic/Latino participants in this cohort were highly educated, with 79% of Hispanic/Latino participants having a college degree or higher. This does not reflect the education level of Hispanic/Latino Americans as a whole. According to the 2022 U.S. census, 26% of Hispanic/Latino respondents had a college degree or higher education level, indicating that our sample is skewed towards a particular subset of Hispanic/Latino individuals in the United States. This may be due in part to recruitment efforts. On several instances, the survey was shared with members of genetics professional societies and with the family and friends of the research team. More research is needed to understand Hispanic/Latino individuals' motivations to participate or not participate in research, as the inclusion of a diverse range of individuals in medical research is of great importance. Failing to do so will perpetuate the lack of diversity in current population

databases, rendering them incomparable in their clinical utility across all ancestral populations.

Vietnamese-speaking participants (n=31) had significantly lower rates of awareness of genetic counseling as compared to their Spanish-speaking and English-speaking counterparts (Pearson's Chi-Square Test, p=0.004). It is documented that Vietnamese Americans view lack of information or misinformation as barriers to uptake of genetic counseling in their communities (Lemke et al., 2022). However, only 42% of Vietnamese-speaking participants in this cohort had a college degree or higher. This rate was statistically significantly lower than the Spanish-speaking or English-speaking cohorts (Pearson's Chi Square test p=0.010). This likely contributed to the lower rates of awareness, as several studies have demonstrated a strong positive correlation between education, awareness of genetic testing, and positive perceptions of genetic testing in Asian patients (Chin et al., 2005; Pagán et al., 2009). However, other studies display that highly educated Asian patients who adopt Western biomedical views simultaneously retain traditional folk beliefs about illness and inheritance that strongly influence their perceptions of genetic counseling (Barlow-Stewart et al., 2006; Eisenbruch et al., 2004). This data highlights the need to explore patients' beliefs on an individual level and not generalize or stereotype.

4.2 Misconceptions about genetic counseling

Four common misconceptions — *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor, When a genetic condition is found in a*

fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy), Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence, and *Genetic Counselors can change a person's genetic makeup* — were identified in our sample (table 13). These misconceptions were even present in those with an education level of college degree or higher, with this subset correctly identifying these misconceptions only 50% of the time, and were particularly prevalent in the Vietnamese-speaking cohort. Overall knowledge scores improved post-intervention for two out of four misconceptions — *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor* (McNemar test, p=0.002) and *When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy)* (McNemar test, p<0.001) — indicating that the video was a successful at educating people about these two topics (table 20).

However, *Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence*, and *Genetic Counselors can change a person's genetic makeup*, remained misconceptions post-intervention (table 21). For the first and second statement, the educational intervention only successfully changed responses from an incorrect to a correct response for 5% (n=4) and 3% (n=2) of participants, which was not a statistically significant improvement (McNemar test, p=0.541), (McNemar test, p=0.839), respectively. These results indicate that beliefs about genetic counselors' ability to change patients' physical or genetic makeup are strongly held and the video intervention was ineffective at significantly influencing these beliefs; therefore, these topics may need more targeted educational efforts.

For Vietnamese-speaking participants specifically, all four misconceptions were strongly held, as scores did not significantly improve for any of these misconceptions. This finding may be congruent with previous findings that some Asian groups will retain some folk beliefs while adopting Western beliefs for other topics. However, more research is needed to uncover best practices for adjusting misconceptions about genetic counselors' abilities to change people's genetic makeup and physical traits. Educational initiatives for this population should incorporate the identification of individual misconceptions and strategize how to best reform these beliefs. It will be important to investigate the root of these misconceptions to better understand how they impact individuals' views of genetic counseling and to better address them.

4.3 Trust

Trust of healthcare institutions and individual providers is an important facet of access. In this study, participants reported high levels of trust and comfortability with genetic counselors. Pre-intervention, 92% of participants agreed or strongly agreed with the statement, "*I think I would feel comfortable making a decision about genetic testing after speaking with a Genetic Counselor*." Privacy is an important component of medical trust and is a concern for many under-represented individuals (Diaz al., 2014; Singer et al., 2004). In this study, 94% of participants agreed with the statement, "*I am confident that my conversations with my Genetic Counselor will be kept private. (Including from my employer, health insurance company, and other family members who see the same provider*)." It is important to replicate these findings in larger cohorts before generalizing conclusions

about the entire population's trust and value in genetic counselors as healthcare professionals.

4.4 Limitations to Access

Pre-intervention, over half of participants (54%) indicated that they believed genetic counseling could benefit at least one of their family members. However, almost half of those who reported it would benefit their family disagreed that genetic counseling was something they could afford (48%). There was not a statistically significant difference in response to this question across preferred language, ethno-racial identity, income, or insurance type, suggesting that in all groups, many participants viewed genetic counseling as financially inaccessible. This indicates that many participants viewed genetic counseling as valuable but unaffordable, despite the fact that only 9% of participants have no health insurance coverage. Financial burden is a documented barrier to genetic counseling in Vietnamese American communities, Black communities, and Hispanic/Latino communities (Chin et al., 2005; Diaz et al., 2004; Lemke et al., 2022; Singer et al., 2004).

Post-intervention, 81% of participants agreed or strongly agreed that they could afford genetic counseling, indicating that the video intervention positively increased patient perception regarding the affordability of genetic counseling (McNemar test, $p<0.001$). Cost is an important perceived and actual barrier to genetic healthcare. Community education initiatives can address perceived concerns about cost by providing education about insurance coverage, expected costs, and financial resources available. However, for some people, the cost of personalized healthcare will continue to be a barrier, despite increased education and support. Therefore, ensuring that genetic testing and appropriate counseling

are financially accessible will remain an essential aspect of reducing health disparities (Matalon et al., 2023).

4.5 Fear

Pre-intervention, over a third of participants (37%) agreed or strongly agreed with the statement, "*I am afraid of my child or myself receiving a genetic diagnosis from a Genetic Counselor*." There was not a significant difference across language or race and ethnicity groups. Unlike concerns about cost, fear was not ameliorated by the educational video, as there was not a statistically significant change in responses post-intervention. This supports previous findings that information about genetic counseling and testing alone does not address fears regarding outcomes of genetic testing (Lemke et al., 2022). Providing information, reducing costs, and protecting privacy can address barriers to patients obtaining genetics-related care, but fear is a barrier that needs to be explored further. Some fears described in previous studies include fear of being surprised or overwhelmed by test results, fear of misuse of genetic information, and fear of discrimination based on genetic test results (Diaz al., 2014; Lemke et al., 2022; Singer et al., 2004). Additional research is needed to determine the foundation of these fears and whether they are due to a generalized fear of healthcare, specific to genetic testing, or stem from another unknown etiology.

4.6 Effects of Provider Video Concordance

For the five biology and basic genetics knowledge questions, provider video concordance did not significantly affect change in scores between the pre-and post-

interventions. However, for the *understanding of genetic counseling* section, concordant provider videos did positively correlate with improvement in knowledge in six of the seven statements in which there was a statistically significant improvement in scores observed (figure 15). These statements were, *Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor* (McNemar test, $p=0.021$), *Genetic counseling is available to people who are planning to become pregnant* (McNemar test, $p=0.012$), *When someone has an illness (like cancer), genetic test results can help their doctors choose an appropriate treatment* (McNemar test, $p<0.001$), *When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy)* (McNemar test, $p<0.035$), *You can see a Genetic Counselor even if no one in your family has ever had a genetic (inherited) condition* $p<0.006$), and *People who are adopted or have limited information about their blood relatives can benefit from genetic counseling* (McNemar test, $p<0.001$). These results indicate that ethno-racial and linguistic concordance between the provider video and the participants improved knowledge scores. It is well documented that provider-patient race and linguistic concordance positively impact patients' perceptions of healthcare, satisfaction with care, and healthcare outcomes, as well as foster improved communication and therapeutic relationship building (Cooper et al., 2003; Greenwood et al., 2019; Jetty et al., 2021; Johnson et al., 2004; Laveist & Nuru-Jeter, 2002; Saha et al., 1999). Much of the existing literature emphasizes the therapeutic advantages and positive health results linked to engaging with a concordant healthcare provider. Nonetheless, an equally crucial goal of genetic counseling is to provide comprehensive and easily comprehensible education. This research has determined that

concordance between the provider and patient could also enhance knowledge acquisition. Moreover, these benefits were observed even in the absence of direct interaction. In the context of genetic counseling and medical genetics, this is a noteworthy new finding that warrants additional investigation. Ensuring that information is communicated in an accessible manner is a crucial aspect of promoting health equity. Patients who have access to understandable and retainable information about their health are better equipped to make informed decisions about their health that align with their values and unique circumstances.

Participants' responses to direct questions about preferences for racially concordant healthcare providers strongly aligned with previous studies that observed individuals from under-represented populations prefer providers from a similar racial, ethnic, and cultural background (table 22) (Han & Lee, 2016; Nimbal et al., 2016). 72% of participants agreed or strongly agreed with the statement, "I believe genetic counselors who share my race or ethnicity can facilitate a more inclusive experience for me." Over two-thirds (69%) of participants felt it was important that their genetic counselor share a similar race or identity as them, indicating that patient-provider concordance is not only a matter of preference but is significant to patients. Nearly two-thirds (64%) responded that only genetic counselors who share their race or ethnicity can fully understand the cultural undertones behind some of their decisions. The high percentage of participants that agreed with this statement indicates that not only are there perceived benefits to concordance, but there may be perceived disadvantages to interacting with a non-concordant provider, as it implies that providers who do not share a patient's race or ethnicity will not understand some or all of their decision-making process.

Language concordance was strongly regarded as important to English, Spanish, and Vietnamese speakers. 89% of participants agreed or strongly agreed with the statement, "It is important to me that my genetic counselor can speak the same language as me without the use of a translator." This aligns with previous studies that revealed Spanish-speaking patients feel more adequately informed, comfortable asking questions, and supported in their decision-making when receiving genetic counseling in their preferred language (Jimenez et al., 2022) and that speakers of Asian languages reported high levels of dissatisfaction with communication and language differences in genetic counseling sessions. (Young, et al., 2021). This is an important finding given that only 4% and less than 1% of genetic counselors report being able to speak Spanish or Vietnamese, respectively (NSGC, 2024). Given the small sample within each language group, we assessed differences based on concordance as a whole and were not able to separate out ethno-racial concordance and language concordance. However, prior research highlights the importance of having providers, educational materials, and support available in a variety of languages.

4.7 Study Limitations

One benefit of provider-patient concordance is improved patient understanding (Jetty et al., 2021). In this study, this benefit was assessed using pre-recorded videos aimed to emulate the experience of interacting with a genetic counselor or clinical geneticist and indicated an improved level of understanding for individuals who received information from a concordant provider. The educational videos were designed to mimic a real session as closely as possible; however, it must be acknowledged that this technique did not capture the interpersonal dynamics of interacting with a provider in real-time. Many central

benefits derive from this interaction between provider and patient. For example, improved communication, shared decision-making, and greater number of questions asked and answered are all benefits that were not able to be evaluated with this study. Other benefits of provider concordance involve improved healthcare outcomes, including adherence to recommendations like medication and screening practices (Jetty et al., 2021). These benefits were also unable to be assessed by a simulated interaction.

To emulate the experience of utilizing a medical interpreter, the original goal was to have each line in the video delivered in English and then repeated in Spanish. However, this would have doubled the length of the interpreter videos. The research team considered this could impact participant retention and dropout and decided against this approach. Instead, subtitles were utilized, which is less similar to a live experience with a provider and interpreter. It is important to acknowledge that in real-time sessions, utilizing an interpreter does increase the time required. When providers are working within strict parameters for time with each patient, a slower session can mean that less information is shared, fewer questions are asked, and less psychosocial counseling is provided, which is a large barrier for non-English-speaking patients.

The video itself appeared to be a barrier to some participants completing the study in its entirety. 45% (n=14 out of 31) of Vietnamese-speaking participants, 19% (n=3 out of 16) of Spanish-speaking participants, and 24% (n=20 out of 83) of English-speaking participants who answered all questions prior to the educational video did not continue beyond that point. This suggests that the video was a significant barrier to the completion of the entire assessment, especially for Vietnamese-speaking participants. The Vietnamese video was the longest at eight minutes and 50 seconds. By comparison, the shortest video

(in English) was five minutes and seven seconds in length. Overall, 44% of Vietnamese-speaking participants, 57% of Spanish-speaking participants, and 80% of English-speaking participants who met inclusion criteria and consented to begin the survey, completed the entire survey.

Another limitation was the low number of participants. Recruitment was confined to 65 days, from February to April 2024. Still, there was less participation than expected. Although recruitment efforts were centered around recruiting Vietnamese and Spanish-speaking participants, there were far more English-speaking participants who began and completed the survey than participants who spoke Spanish or Vietnamese. It is possible that these findings reflect persistent low levels of trust in research among the public. Thoughtful examination of effective recruitment strategies for future studies is necessary, especially to gain a deeper understanding of why individuals who do not speak English are less inclined to participate in this type of research. Steps can be taken to develop studies that are more inclusive and accessible to these individuals.

The survey design did not involve community advocates, and all survey creators had at least a college degree. Although attempts were made to construct questions at a seventh-grade reading level, there were no checks in place to ensure accessibility to participants at various reading levels. Consequently, some questions may have been misinterpreted due to their wording. In previous studies, a fourth-grade reading level was chosen to ensure accessibility for lower literacy participants (Hillyer et al., 2020). This may have been a more suitable choice, and a seventh-grade reading level may have been too advanced for some of the participants in this study. This underscores the crucial role of actively involving members of a research target group in the research process.

4.8 Future Directions

Underrepresented groups receive less education from the American healthcare system, due in part to language barriers. For immigrant populations, there is a positive association between acculturation to the United States, including English proficiency, and awareness of genetic testing (Pagán et al., 2009). Future educational efforts should steer away from blanket approaches that target all under-represented groups and instead focus on targeting specific sub-groups individually. Our study and prior research demonstrate that presenting information in culturally relevant media platforms in native languages has strong abilities to close knowledge gaps (Pagán et al., 2009, Hillyer et al., 2020).

Lack of information about medical genetics is a significant barrier to Asian American patients (Chin et al., 2005; Lemke et al., 2022). It is crucial to educate this population, as it will be a vital step towards achieving equitable healthcare outcomes. A survey of Vietnamese American participants found that Vietnamese Americans believe that community education to increase awareness of genetic counseling and testing is necessary. Participants stated that genetic education would be best received from a primary care provider or other medical professional with whom they have already established trust. However, in order for this delivery model to be successful, it is imperative that primary care providers receive comprehensive education in genetics (Jooma et al., 2019). The participants also emphasized that delivering education through Vietnamese-language media, including social media, community news outlets, and television, as well as through community events at local clinics or pharmacies, would be effective strategies. Additionally, participants highlighted the need for the inclusion of Vietnamese interpreters when

explaining genetic information to those with limited English proficiency (Lemke et al., 2022). We know that some communities will still retain traditional folk beliefs after education about Western views of genetics. Rather than discrediting these beliefs, genetic counselors can incorporate their patients' individual belief systems into education in a nonjudgmental way that avoids stereotyping (Barlow-Stewart et al., 2006; Eisenbruchet al., 2004).

Research such as that conducted by Lemke et al., which derives recommendations directly from the input of individuals with lived experience, is imperative for gaining a more comprehensive understanding of how different groups prefer to receive information. Similarly, the research community would benefit from an increased understanding of the motivations behind the participation or non-participation of historically underrepresented populations in medical, and specifically genetics research, including barriers towards participating in research in which they are interested, to expand the inclusion of these groups in future research and improve participant retention.

One potential explanation for low levels of engagement of non-English speaking individuals with this survey was that community advocates were not included in the design of the survey. Community-based participatory research (CBPR) is a model that involves research participants in the research process, thereby allowing them to make an impact in their own communities. This model has been proven to improve health outcomes in many settings. CBPR has demonstrated success in recruiting populations for genetics studies. When used to recruit Pacific Islanders into a genetics study, CBPR yielded a recruitment rate of 96%, with the majority of participants reporting their motivation to participate centered around their desire to contribute to the health of their community (McElfish et al.,

2017, Hillyer et al., 2020). Fostering relationships between researchers and community members improves trust, transparency, and sustainability. CBPR is most successful when an ongoing relationship between the community and researchers is maintained, local cultural knowledge is integrated, and efforts are supported by larger-scale policymakers (Simonds et al., 2013; Thompson et al., 2016).

In the absence of linguistically concordant providers, healthcare systems should consider that communicating with a patient through an interpreter increases the time needed to provide adequate care. Healthcare providers and systems can ensure health equity across patients by planning longer appointment times for sessions requiring an interpreter.

This study supports the body of literature that demonstrates the benefits of the availability of ethno-racially diverse healthcare providers. However, there are many profound financial and other barriers that prevent prospective students with fewer intergenerational resources from entering the genetic counseling profession. It will be important to explore evidence-based strategies to decrease these barriers to entry in order to diversify our workforce (Lee, et al. 2024).

4.9 Conclusions

The intervention generally led to significant improvements in participants' understanding of genetic counseling and testing. This indicates that educational interventions involving video materials are effective in improving public knowledge about genetic counseling. However, persistent misconceptions in certain areas, such as genetic

counselors' ability to change physical and genetic makeup, suggest these topics may need more targeted educational efforts.

Achieving health and genomic equity remains a challenge due to the continued underrepresentation of non-White populations in research and barriers to genetic services. It is imperative that historically and currently marginalized groups receive adequate health care. This research contributes to the existing body of literature that demonstrates historically marginalized groups' preference for healthcare providers who share their ethnic, racial, and linguistic backgrounds. It also suggests that even without direct interaction, receiving information from a provider who shares the same background can lead to increased knowledge acquisition among marginalized groups. If the study had been conducted only in English, 35% of the participants who preferred another language (Spanish or Vietnamese), would have been excluded. Given the known benefits of provider-patient ethno-racial and linguistic concordance, diversifying our predominantly homogeneous workforce to increase access to concordant providers for non-White patients is imperative. In the meantime, accommodations, such as access to medical interpreters familiar with genetics, flexibility accommodating patients' preferred family into genetic counseling visits, increasing appointment times or utilizing resources in languages other than English to collect medical and family history information ahead of an appointment, can all improve health equity for patients who do not have access to a concordant provider. Additionally, future studies, that include community members in the research process, are necessary to better understand how to best provide genetic health information to groups with lower levels of understanding and to improve accessibility of research participation to non-White and non-English speaking groups.

REFERENCES

Alvarado, M., Tiller, G. E., Chung, J., & Haque, R. (2020). Prevalence of mutations in a diverse cohort of 3162 women tested via the same multigene cancer panel in a managed care health plan. *Journal of Community Genetics*, *11*(3). https://doi.org/10.1007/s12687-020-00456-6

Anderson, K. M. (2012). *How Far Have We Come in Reducing Health Disparities? Progress Since 2000*. National Academy of Sciences.

Barlow-Stewart, K., Yeo, S. S., Meiser, B., Goldstein, D., Tucker, K., & Eisenbruch, M. (2006). *Toward cultural competence in cancer genetic counseling and genetics education: Lessons learned from Chinese-Australians*. https://doi.org/10.1097/01.gim.0000195884.86201.a0

Bean, M. G., Focella, E. S., Covarrubias, R., Stone, J., Moskowitz, G. B., & Badger, T. A. (2015). Author manuscript; available in PMC. In *J Health Dispar Res Pract* (Vol. 7, Issue 4).

Bonham, V. L., & Green, E. D. (2021). The genomics workforce must become more diverse: a strategic imperative. https://doi.org/10.1016/j.ajhg.2020.12.013

Buseh, A., Kelber, S., Millon-Underwood, S., Stevens, P., & Townsend, L. (2014). Knowledge, group-based medical mistrust, future expectations, and perceived disadvantages of medical genetic testing: Perspectives of black African immigrants/refugees. *Public Health Genomics*, *17*(1), 33–42. https://doi.org/10.1159/000356013

Canedo, J. R., Miller, S. T., Myers, H. F., & Sanderson, M. (2019). Racial and ethnic differences in knowledge and attitudes about genetic testing in the US: Systematic review. In *Journal of Genetic Counseling* (Vol. 28, Issue 3, pp. 587–601). John Wiley and Sons Inc. https://doi.org/10.1002/jgc4.1078

Chin, T.-M., Tan, S.-H., Lim, S.-E., Iau, P., Yong, W.-P., Wong, S.-W., & Lee, S.-C. (2005). *Acceptance, motivators, and barriers in attending breast cancer genetic counseling in Asians*. https://doi.org/10.1016/j.cdp.2005.06.009

Cooper, L. A., Roter, D. L., Johnson, R. L., Ford, D. E., Steinwachs, D. M., & Powe, N. R. (2003). Patient-centered communication, ratings of care, and concordance of patient and physician race. *Annals of Internal Medicine*, *139*(11), 907. https://doi.org/10.7326/0003-4819-139-11-200312020-00009

de Leon, A., Mccarthy Veach, P., della Bro, |, & Leroy, B. S. (2022). Spanish language concordance in genetic counseling sessions in the United States: Counselor experiences and perceptions of its effects on processes and outcomes. *J Genet Couns*, *31*, 188–205. https://doi.org/10.1002/jgc4.1472

Diaz, V. A., Mainous, A. G., Gavin, J. K., & Wilson, D. (2014). Racial differences in attitudes toward personalized medicine. *Public Health Genomics*, *17*(1), 1–6. https://doi.org/10.1159/000354785

Eisenbruch, M., Yeo, S. S., Meiser, B., Goldstein, D., Tucker, K., & Barlow-Stewart, K. (2004). Optimising clinical practice in cancer genetics with cultural competence: lessons to be learned from ethnographic research with Chinese-Australians. *Social Science & Medicine*, *59*, 235–248. https://doi.org/10.1016/j.socscimed.2003.10.016

Fitzgerald, C., & Hurst, S. (2017). Implicit bias in healthcare professionals: A systematic review. *BMC Medical Ethics*, *18*(1). https://doi.org/10.1186/s12910-017-0179-8

Hagiwara, N., Duffy, C., & Quillin, J. (2023). Implicit and explicit racial prejudice and stereotyping toward Black (vs. White) Americans: The prevalence and variation among genetic counselors in North America. *Journal of Genetic Counseling*, *32*(2). https://doi.org/10.1002/jgc4.1648

Halbert, C. H., & Harrison, B. W. (2018). Genetic counseling among minority populations in the era of precision medicine. *American Journal of Medical Genetics, Part C: Seminars in Medical Genetics*, *178*(1), 68–74. https://doi.org/10.1002/ajmg.c.31604

Han, W., & Lee, S. (2016). *Social Work in Health Care Racial/ethnic variation in health care satisfaction: The role of acculturation*. https://doi.org/10.1080/00981389.2016.1191580

Hann, K. E. J., Freeman, M., Fraser, L., Waller, J., Sanderson, S. C., Rahman, B., Side, L., Gessler, S., & Lanceley, A. (2017). *Awareness, knowledge, perceptions, and attitudes towards genetic testing for cancer risk among ethnic minority groups: a systematic review*. https://doi.org/10.1186/s12889-017-4375-8

Hillyer, G. C., Schmitt, K. M., Reyes, A., Cruz, A., Lizardo, M., Schwartz, G. K., & Terry, M. B. (2020). Community education to enhance the more equitable use of precision medicine in Northern Manhattan. *Journal of Genetic Counseling*, *29*(2), 247–258. https://doi.org/10.1002/jgc4.1244

Hughes Halbert, C., Kessler, L., Collier, A., Weathers, B., Stopfer, J., Domchek, S., & McDonald, J. A. (2012). *Low Rates of African American Participation in Genetic Counseling and Testing for BRCA1/2 Mutations: Racial Disparities or Just a Difference?* https://doi.org/10.1007/s10897-012-9485-y

Iredale, R. (2000). Eugenics and Its Relevance to Contemporary Health Care. *Nursing Ethics.*

Jetty, A., Jabbarpour, Y., Pollack, J., Huerto, R., Woo, S., & Petterson, S. (2021). Patient-Physician Racial Concordance Associated with Improved Healthcare Use and Lower Healthcare Expenditures in Minority Populations. *Journal of Racial and Ethnic Health Disparities*. https://doi.org/10.1007/s40615-020-00930-4/Published

Jimenez, S., Matthews, A., Darrah, R., Schreiber, | Allison, Ricker, C., Kami, |, & Schneider, W. (2023). Perspectives on Spanish language concordant cancer genetic counseling sessions from the Spanish-speaking population. *J Genet Couns*, *32*, 111–127. https://doi.org/10.1002/jgc4.1628

Johnson, R. L., Roter, D., Powe, N. R., & Cooper, L. A. (2004). Patient Race/Ethnicity and Quality of Patient-Physician Communication During Medical Visits. *Research and Practice* (Vol. 94, Issue 12).

Johnson, T. J., Winger, D. G., Hickey, R. W., Switzer, G. E., Miller, E., Nguyen, M. B., Saladino, R. A., & Hausmann, L. R. M. (2017). Comparison of physician implicit racial bias toward adults versus children. *Academic Pediatrics*, *17*(2), 120–126. https://doi.org/10.1016/j.acap.2016.08.010

Jooma, S., Hahn, M. J., Hindorff, L. A., & Bonham, V. L. (2019). Defining and achieving health equity in genomic medicine. Ethnicity & Disease, 29(Suppl 1), 173–178. https://doi.org/10.18865//ed.29.s1.173

Kutner, M., Greenburg, E., Jin, Y., & Paulsen, C. (2006). The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy. NCES 2006-483. *National Center for Education Statistics*.

Laveist, T. A., & Nuru-Jeter, A. (2002). Is Doctor-Patient Race Concordance Associated with Greater Satisfaction with Care? In *Source: Journal of Health and Social Behavior* (Vol. 43, Issue 3). http://www.jstor.orgURL:http://www.jstor.org/stab

Lee, D., Platt, J., Flodman, P., Singh, K.E., Quintero-Rivera, F. (2004). Analysis of Financial Barriers Experienced by Prospective Genetic Counseling Students. *Genetics in Medicine.*

Lemke, A. A., Choi, S. H., Dang, V., Dang, T. Q., & Yu, J.-H. (2022). *Assessing Vietnamese American patient perspectives on population genetic testing in primary care: A community-engaged approach*. https://doi.org/10.1016/j.xhgg.2022.100134

Lowe, C., Beach, M. C., & Roter, D. L. (2020). Individuation and Implicit Racial Bias in Genetic Counseling Communication HHS Public Access. *Patient Educ Couns*, *103*(4), 804–810. https://doi.org/10.1016/j.pec.2019.10.016

Madden, E. B., Hindorff, L. A., Bonham, V. L., Akintobi, T. H., Burchard, E. G., Baker, K. E., Begay, R. L., Carpten, J. D., Cox, N. J., Di Francesco, V., Dillard, D. A., Fletcher, F. E., Fullerton, S. M., Garrison, N. A., Hammack-Aviran, C. M., Hiratsuka, V. Y., Hildreth, J. E., Horowitz, C. R., Hughes Halbert, C. A., … Green, E. D. (2024). Advancing genomics to improve health equity. Nature Genetics, 56(5), 752–757. https://doi.org/10.1038/s41588-024-01711-z

Matalon, D. R., Zepeda-Mendoza, C. J., Aarabi, M., Brown, K., Fullerton, S. M., Kaur, S., Quintero-Rivera, F., & Vatta, M. (2023). Clinical, technical, and environmental biases influencing equitable access to clinical genetics/genomics testing: A points to consider statement of the

American College of Medical Genetics and Genomics (ACMG). *Genetics in Medicine*, *25*(6), 100812. https://doi.org/10.1016/j.gim.2023.100812

Matalon, D. R., Zepeda-Mendoza, C. J., Aarabi, M., Brown, K., Fullerton, S. M., Kaur, S., McCarthy Veach, P., LeRoy, B. S., & Callanan, N. P. (2018). Overview of genetic counseling: History of the profession and the reciprocal-engagement model of Practice. *Facilitating the Genetic Counseling Process*, 33–49. https://doi.org/10.1007/978-3-319-74799-6_2

Mcelfish, P. A., Narcisse, M.-R., Long, C. R., Ayers, B. L., Hawley, N. L., Aitaoto, N., Riklon, S., Su, & L. J., Ima, S. Z., Wilmoth, R. O., Schulz, T. K., Kadlubar, S., & Su, L. J. (2017). Leveraging community-based participatory research capacity to recruit Pacific Islanders into a genetics study. *J Community Genet*, *8*, 283–291. https://doi.org/10.1007/s12687-017-0313-9

Moberg, S. P., Krysan, M., & Christianson, D. (2019). Racial Attitudes in America. In *Public Opinion Quarterly* (Vol. 83, Issue 2, pp. 450–471). Oxford University Press. https://doi.org/10.1093/poq/nfz014

Nosek, B. A., Smyth, F. L., Hansen, J. J., Devos, T., Lindner, N. M., Ranganath, K. A., Smith, C. T., Olson, K. R., Chugh, D., Greenwald, A. G., & Banaji, M. R. (2007). Pervasiveness and correlates of implicit attitudes and stereotypes. *European Review of Social Psychology*, *18*(1). https://doi.org/10.1080/10463280701489053

Pagán, J. A., Su, D., Li, L., Armstrong, K., & Asch, D. A. (2009). Racial and Ethnic Disparities in Awareness of Genetic Testing for Cancer Risk. *American Journal of Preventive Medicine*, *37*(6), 524–530. https://doi.org/10.1016/J.AMEPRE.2009.07.021

Paul, D. (1997). From eugenics to medical genetics. *Journal of Policy History*, *9*(1), 96–116. https://doi.org/10.1017/s0898030600005844

Pollock, B., Wetherill, L., Delk, P., Wesson, M., Rucker, S., Goodman, Z., Remeika, W., & Ivanovich, J. (2022). Diversity training experiences and factors associated with implicit racial bias among recent genetic counselor graduates of accredited programs in the United States and Canada. *Journal of Genetic Counseling*, *31*(3), 792–802. https://doi.org/10.1002/jgc4.1547

Professional Status Survey 2024: Executive summary. (2024). https://www.nsgc.org/Portals/0/Docs/Policy/PSS%202024%20Executive%20Summary_Final.pdf?ver=xMyKy1O8H749GCBpxy6NiA%3d%3d

Reardon, S.F. & Owens, A. (2014)60 Years After Brown: Trends and Consequences of School Segregation. *The Annual Review of Sociolog,* 10.1146/annurev-soc-071913-043152

Quintero-Rivera, F., & Hisama, F. M. (2020). Diversity, inclusion and equity in Medical Genetics: The time is now. *American Journal of Medical Genetics Part A*, *182*(12), 2817–2819. https://doi.org/10.1002/ajmg.a.61899

Resta, R., Bowles Biesecker, B., Bennett, R. L., Blum, S., Hahn, S. E., Strecker, M. N., & Williams, J. L. (2006). A New Definition of Genetic Counseling: National Society of Genetic Counselors' Task Force Report The National Society of Genetic Counselors' Definition Task Force. *Journal of Genetic Counseling*, *15*(2). https://doi.org/10.1007/s10897-005-9014-3

Rosenbaum, M., Dineen, | Richard, Schmitz, K., Stoll, J., Hsu, M., & Hodges, P. D. (2020). *Interpreters' perceptions of culture bumps in genetic counseling Graduate Program in Genetic Counseling*. https://doi.org/10.1002/jgc4.1246

Saha, S., Komaromy, M., Koepsell, T. D., & Bindman, A. B. (1999). Patient-physician racial concordance and the perceived quality and use of health care. Archives of Internal Medicine, 159(9), 997. https://doi.org/10.1001/archinte.159.9.997

Schaa, K. L., Roter, D. L., Biesecker, B. B., Erby, L. H., & Author, H. P. (2015). Genetic counselors' implicit racial attitudes and their relationship to communication HHS Public Access Author manuscript. *Health Psychol*, *34*(2), 111–119. https://doi.org/10.1037/hea0000155

Singer, E., Antonucci, T., & van Hoewyk, J. (2004). Racial and Ethnic Variations in Knowledge and Attitudes about Genetic Testing. *Genetic Testing*, *8*(1), 31–43. https://doi.org/10.1089/109065704323016012

Singer, E., Couper, M. P., Raghunathan John Van Hoewyk, T. E., & Antonucci, T. C. (2008). Trends in U.S. Attitudes Toward Genetic Testing, 1990–2004.*72*(3), 446–458. https://doi.org/10.1093/poq/nfn033

Southwick, S. v., Esch, R., Gasser, R., Cragun, D., Redlinger-Grosse, K., Marsalis, S., & Zierhut, H. A. (2020). Racial and ethnic differences in genetic counseling experiences and outcomes in the United States: A systematic review. *Journal of Genetic Counseling*, *29*(2), 147–165. https://doi.org/10.1002/jgc4.1230

Suther, S., & Kiros, G. E. (2009). Barriers to the use of genetic testing: A study of racial and ethnic disparities. *Genetics in Medicine*, *11*(9), 655–662. https://doi.org/10.1097/GIM.0b013e3181ab22aa

Thompson, B., Molina, Y., Viswanath, K., Warnecke, R., & Prelip, M. L. (2016). *Addressing Disparities*. *35*. https://doi.org/10.1377/hlthaff.2015.1364

Thompson, H. S., Valdimarsdottir, H. B., Jandorf, L., & Redd, W. (2003). Perceived disadvantages and concerns about abuses of genetic testing for cancer risk: differences across African American, Latina and Caucasian women. *Patient Education and Counseling*, *51*(3), 217–227. https://doi.org/10.1016/S0738-3991(02)00219-7

U.S. Department of Health and Human Services. (2019). *Not-OD-20-031: Notice of NIH's interest in Diversity*. National Institutes of Health. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-20-031.html

US household income distribution data, shown in one chart | World Economic Forum. Retrieved May 22, 2024, from https://www.weforum.org/agenda/2022/07/household-income-distribution-wealth-inequality-united-states/#

Weindling, P. (1993). The Survival of Eugenics in 20th-Century Germany. In *Am. J. Hum. Genet* (Vol. 52).

Whelan, A. M. (2020). Unequal Representation: Women in Clinical Research. In *106 Cornell L. Rev. Online* (Vol. 87). https://heinonline.org/HOL/License

Young, J. L., Mak, J., Stanley, T., Bass, M., Cho, M. K., & Tabor, H. K. (2021). *Genetic counseling and testing for Asian Americans: a systematic review*. https://doi.org/10.1038/s41436-021-01169-y

Zestcott, C. A., Blair, I. v., & Stone, J. (2016). Examining the presence, consequences, and reduction of implicit bias in health care: A narrative review. In *Group Processes and Intergroup Relations* (Vol. 19, Issue 4). https://doi.org/10.1177/1368430216642029

Appendix A: Letter of Confirmation for Self-Determination Process

University of California, Irvine

Office of Research
160 Aldrich Hall
Irvine, CA 92697-7600

January 2024

THE EXEMPT SELF DETERMINATION PROCESS AT UCI

To Whom it May Concern:

The Exempt Self-Determination process may be used to self-determine certain types of exempt research at UCI, including exempt research conducted through the Undergraduate Research Opportunities Program (UROP). Exceptions do apply. Please refer to the Exempt Self Determination webpage on this topic. The Exempt Self-Determination process is initiated through Kuali Research Protocols (KRP).

As part the Exempt Self-Determination process, if a study is eligible for self-determination, UCI IRB review is not required and will not be provided. In an effort to reduce administrative burden, the IRB has delegated this responsibility for *specific exempt categories*, to UCI Faculty Researchers. Should a sponsor inquire if the Exempt Self-Determination process, once complete, equates to an official UCI IRB confirmation of exemption, the answer is, "yes."

For studies that are submitted to the IRB where the Exempt Self-Determination process may be used instead, the study will be returned to the researcher to self-determine. In addition, amendments to studies that have undergone the self-determination process are to be maintained independently. No amendments should be submitted in KRP unless a change to the self-determined protocol results in the study no longer being eligible for self-determination. For exempt or expedited studies that require UCI IRB review, Lead Researchers must submit an IRB Application in KRP.

UROP students using the Exempt Self-Determination process in KRP to conduct exempt research should contact UROP for questions related to the use of the tool.

As part of using the Exempt Self-Determination process at UCI, Lead Researchers and Faculty Sponsors (as applicable) provide their assurance that they will follow relevant Human Research Protection Program (HRPP) policies and procedures, among other criteria. For a copy of the assurance, please review the following page.

If you have any questions or comments, please contact HRP Staff.

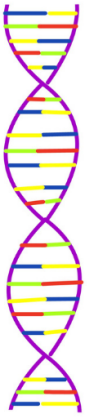
Appendix B: Recruitment Materials

Do you worry about a medical condition that runs in your family?

Researchers at the
University of California, Irvine
School of Medicine
are looking for participants who are interested in taking an anonymous survey and learning about DNA and how genetic counseling is used to help people and their families.

What will participants do?

- take anonymous survey
- watch a short educational video
- answer a few more questions
- learn about genetic counseling and how it relates to them!
- Participation will take about 15-20 minutes



Are you eligible?

anyone can participate as long as they are:

- 18 or older
- currently living in the US

(do not need to be a US citizen)

Participants will receive:

- INFORMATION ABOUT GENETIC COUNSELING
- A CHANCE TO SHARE THEIR THOUGHTS ABOUT THEIR HEALTHCARE
- CHANCE TO ENTER RAFFLE FOR 1 OF 10 $25 GIFT CARDS TO THEIR CHOICE OF AMAZON, STARBUCKS, OR TARGET

go to bit.ly/surveyuci
or scan this QR code to start the anonymous survey!

UCI School of Medicine

Questions?

Please email
lead researcher, Greer Hennessy
ghenness@hs.uci.edu
or Faculty Sponsor, Dr. Quintero-Rivera
fabiolaq@hs.uci.edu

Do you worry about a medical condition that runs in your family?

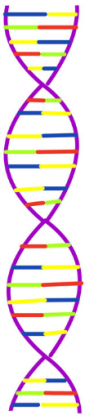
Latina/o Voices are under-represented in medical genetics research.

Researchers at the University of California, Irvine School of Medicine want to change this.

Do you want to be a part of this change while learning about DNA and how genetic counseling is used to help people and their families?

What will participants do?

- take anonymous survey
- watch a short educational video
- answer a few more questions
- learn about genetic counseling and how it relates to them!
- Participation will take about 15-20 minutes



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UCI School of Medicine

Questions?

Please email
lead researcher, Greer Hennessy
ghenness@hs.uci.edu
or Faculty Sponsor, Dr. Quintero-Rivera
fabiolaq@hs.uci.edu

¿Hay alguna enfermedad en varios miembros de su familia que le preocupe?

Las voces latino/as están subrepresentadas en los proyectos de investigación de genética médica.

Investigadores de la Facultad de Medicina de la Universidad de California Irvine (UCI) quieren cambiar esta situación.

¿Le gustaría formar parte de esté cambio y a la vez aprender sobre el ADN (DNA) y cómo se utiliza el asesoramiento genético para ayudar a las personas y a sus familias?

¿Qué harán los participantes?

- responder a una encuesta anónima
- ver un breve vídeo educativo
- responder a algunas preguntas más
- informarse sobre el asesoramiento genético y su utilidad
- La encuesta durará entre 15 y 20 minutos.

¿Eres elegible?

Puede participar cualquier persona siempre que :

-tenga 18 años o más
-vivan actualmente en Estados Unidos
(no es necesario ser ciudadano estadounidense)

Los participantes recibirán:

INFORMACIÓN SOBRE ASESORAMIENTO GENÉTICO

LA OPORTUNIDAD DE COMPARTIR SUS OPINIONES SOBRE SU CUIDADO DE SALUD

LA OPORTUNIDAD DE PARTICIPAR EN EL SORTEO DE 1 DE LAS 10 TARJETAS REGALO DE $25, PODRA ELEGIR ENTRE AMAZON, STARBUCKS O TARGET

ir a bit.ly/surveyuci o
escanee aquí para comenzar
la encuesta anónima

¿Tiene Preguntas?

envíe un correo electrónico
investigador principal,
Greer Hennessy
ghenness@hs.uci.edu
or Profesora patrocinadora,
Dr. Quintero-Rivera
fabiolaq@hs.uci.edu

Do you worry about a medical condition that runs in your family?

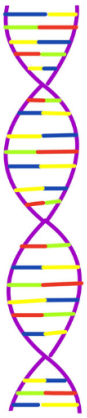
Vietnamese voices are under-represented in medical genetics research.

Researchers at the University of California, Irvine School of Medicine want to change this.

Do you want to be a part of this change while learning about DNA and how genetic counseling is used to help people and their families?

What will participants do?

- take anonymous survey
- watch a short educational video
- answer a few more questions
- learn about genetic counseling and how it relates to them!
- Participation will take about 15-20 minutes



Are you eligible?

anyone can participate as long as they are:

- 18 or older
- currently living in the US

(do not need to be a US citizen)

go to bit.ly/surveyuci
or scan this QR code to start the anonymous survey!

Participants will receive:

- INFORMATION ABOUT GENETIC COUNSELING
- A CHANCE TO SHARE THEIR THOUGHTS ABOUT THEIR HEALTHCARE
- CHANCE TO ENTER RAFFLE FOR 1 OF 10 $25 GIFT CARDS TO THEIR CHOICE OF AMAZON, STARBUCKS, OR TARGET

Questions?

Please email
lead researcher, Greer Hennessy
ghenness@hs.uci.edu
or Faculty Sponsor, Dr. Quintero-Rivera
fabiolaq@hs.uci.edu

CÓ TÌNH TRẠNG BỆNH LÝ NÀO TRONG GIA ĐÌNH BẠN MÀ BẠN LO LẮNG KHÔNG?

Tiếng nói của người Việt Nam ít được thể hiện trong nghiên cứu về gen di truyền.

Các nhà nghiên cứu tại Đại học California, Irvine muốn thay đổi điều đó.

Bạn có muốn trở thành một phần của sự thay đổi này và hiểu biết thêm về việc làm thế nào tư vấn gen di truyền giúp đỡ mọi người và gia đình họ?

Người tham gia sẽ làm gì?

- Làm khảo sát ẩn danh
- Xem một video giáo dục ngắn
- Trả lời thêm một số câu hỏi
- Hiểu thêm về tư vấn gen di truyền và nó liên quan gì đến với người tham gia!
- Cuộc khảo sát sẽ mất khoảng 15-20 phút.

Bạn có đủ tiêu chuẩn không?

Mọi người có thể tham gia nếu họ:

- 18 tuổi hoặc lớn hơn
- hiện đang sống ở Hoa Kỳ

(không cần phải là công dân Hoa Kỳ)

NHỮNG NGƯỜI THAM GIA SẼ NHẬN ĐƯỢC:

THÔNG TIN VỀ TƯ VẤN GEN DI TRUYỀN

MỘT CƠ HỘI ĐỂ CHIA SẺ SUY NGHĨ CỦA HỌ VỀ VIỆC CHĂM SÓC SỨC KHOẺ

CƠ HỘI ĐỂ THAM GIA XỔ SỐ CHO 1 TRONG 10 THẺ QUÀ TẶNG $25 CHO SỰ LỰA CHỌN GIỮA AMAZON, STARBUCKS, HOẶC TARGET

https://bit.ly/surveyuci

Câu hỏi?

Xin gửi email cho nhà nghiên cứu chính, Greer Hennessy
ghenness@hs.uci.edu
hoặc giảng viên tài trợ, Dr. Quintero-Rivera
fabiolaq@hs.uci.edu

Do you worry about a medical condition that runs in your family?

Black/African American Voices are under-represented in genetics research.

Researchers at the University of California, Irvine School of Medicine want to change this.

Do you want to be a part of this change while learning about DNA and how genetic counseling is used to help people and their families?

What will participants do?

- take anonymous survey
- watch a short educational video
- answer a few more questions
- learn about genetic counseling and how it relates to them!
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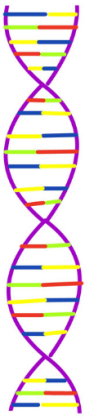

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Questions?

Please email
lead researcher, Greer Hennessy
ghenness@hs.uci.edu
or Faculty Sponsor, Dr. Quintero-Rivera
fabiolaq@hs.uci.edu

Appendix C: Organizations to Which Recruitment Material Was Distributed

UCI Department of Chicano/Latino Studies
UCI Department of East Asian Studies
Chao Office of Community Engagement and Outreach
UCI Center for Black Cultures, Resources & Research
Latinx Files LA times
VietRISE
The National Organization for Vietnamese American Leadership of Greater Washington, DC (NOVAL-DC)
Vietnamese American Services
Vietnamese American Organization
Vietnamese American Civic Association, Inc
Black Mamas Matter Alliance
African American Leadership Forum
The Samuel DeWitt Proctor Conference (SDPC)
Our Black San Diego
Southland Integrated Services, Inc.
Vital Access Care Foundation
Cancer Care Spanish Support Group
Cancer Support Community Los Angeles Spanish Group
Melinda Hoag Smith Center for Healthy Living Spanish Support Group
Latino Outdoors
Vietnamese Cancer Awareness Research and Education Society
The Leukemia & Lymphoma Society–Southern CA/Hawaii

Appendix D: Study Information Sheet- English

University of California, Irvine
Study Information Sheet

Assessing the Impact of Provider-Patient Race and Linguistic Concordance on Knowledge and Attitudes of Underrepresented Populations towards Genetic Counseling

Lead Researcher
Greer Hennessy
Division of Genetic and Genomic Medicine
ghenness@hs.uci.edu

Faculty Sponsor
Fabiola Quintero-Rivera, MD, FACMG
Professor, Department of Pathology and Laboratory Medicine
Director, Laboratory of Clinical Cytogenetics and Genomics
Division of Genetic and Genomic Medicine
fabiolaq@hs.uci.edu

Please read the information below. Please email one of the researchers listed above if there is anything you don't understand, and we will be available to answer your questions.

- You are being asked to participate in a research study. Participation in this study is voluntary. You may choose to skip a question or a study procedure. You may refuse to participate or discontinue your involvement at any time without penalty or loss of benefits. You are free to withdraw from this study at any time. **If you decide to withdraw from this study you should notify the research team immediately**.

- We would like you to complete an anonymous survey so we can learn more about how individuals from different populations learn about genetics and genetic counseling. You will be asked a series of questions, then watch a short informational video, and then answer a few more questions. The whole survey will last about 20 minutes.

- Possible risks/discomforts associated with the study are an invasion of your privacy and a potential for a breach of confidentiality.

- However, all research data collected will be stored securely and confidentially. It will be maintained electronically and will be password protected and maintained in an encrypted format.

- There are no direct benefits from participation in the study. However, participants who complete the survey will learn about genetics, genetic counseling, and how they can learn more about their family's health.

- You will be able to enter a raffle for one of 10 $25 gift cards for your participation in this study. Winners can choose between a gift card to either Amazon, Target, or Starbucks. Participation in the raffle is voluntary and separate from participation in the survey. If you choose to enter the raffle, a link will be provided to leave your email address. These responses will be stored separately from the survey responses and your email address will not be linked to your survey responses.

- Researchers will use your information to conduct this study. Once the study is done using your information, we may share them with other researchers so they can use them for

other studies in the future. We will not share your name or any other private identifiable information that would let the researchers know who you are. We will not ask you for additional permission to share this de-identified information.

- Questions? If you have any comments, concerns, or questions regarding this study please contact the researchers listed at the top of this form.

- If you have questions or concerns about your rights as a research participant, you can contact the UCI Institutional Review Board by phone, (949) 824-8170, by e-mail at IRB@research.uci.edu or at 160 Aldrich Hall, Irvine, CA 92697-7600.

  What is an IRB? An Institutional Review Board (IRB) is a committee made up of scientists and non-scientists. The IRB's role is to protect the rights and welfare of human subjects involved in research. The IRB also assures that the research complies with applicable regulations, laws, and institutional policies.

- If you want to participate in this study, click the "agree" button to start the survey.

Study Information Sheet- Spanish

University of California, Irvine
Hoja Informativa del Estudio

Evaluación del Impacto de la Concordancia Racial y Lingüística del Proveedor de salud yel Paciente en el Conocimiento y actitudes hacia el asesoramiento genético en las poblaciones subrepresentadas

Investigador principal
Greer Hennessy
División de Medicina Genética y Genómica
ghenness@hs.uci.edu

Faculty Sponsor
Fabiola Quintero-Rivera, MD, FACMG
Profesor, Departamento de Patología y Medicina de Laboratorio
Director, Laboratorio de Citogenética Clínica y Genómica
División de Medicina Genética y Genómica
fabiolaq@hs.uci.edu

Lea la información que figura a continuación. Si hay algo que no entienda, envíe un correo electrónico a uno de los investigadores que figuran arriba; estaremos a su disposición para responder a sus preguntas.

Lo invitamos a que participe en un estudio de investigación. La participación en este estudio es voluntaria. Puede optar por omitir una pregunta del estudio. Puede negarse a participar o interrumpir su participación en cualquier momento sin penalización ni pérdida de beneficios. Usted es libre de retirarse de este estudio en cualquier momento. Si decide retirarse de este estudio debe notificarlo inmediatamente al equipo de investigación.

Nos gustaría que completara una encuesta anónima para que podamos saber más sobre cómo aprenden sobre genética y asesoramiento genético las personas de distintos grupos de población. Se le harán una serie de preguntas, después verá un breve vídeo informativo y a continuación responderá a algunas preguntas más. Completar la encuesta durará unos 20 minutos.

Los posibles riesgos/incomodidades asociados con el estudio son la posibilidad de sentir incomodidad al responder preguntas personales".

No obstante, todos los datos de investigación recopilados se almacenarán de forma segura y confidencial. Se conservarán electrónicamente, estarán protegidos por contraseña y se mantendrán en un formato cifrado.

La participación en el estudio no le traera beneficios directos. Sin embargo, los participantes que completen la encuesta aprenderán sobre genética, asesoramiento genético y cómo pueden saber más sobre la salud de su familia.

Podrá entrar en el sorteo de una de las 50 tarjetas de regalo de $5 por su participación en este estudio. Los ganadores podrán elegir entre una tarjeta regalo para Amazon, Starbucks o Target. La participación en el sorteo es voluntaria e independiente de la participación en la encuesta. Si decide participar en el sorteo, se le proporcionará un enlace para que deje su

dirección de correo electrónico. Estas respuestas se almacenarán separadas de las respuestas a la encuesta y su dirección de correo electrónico no se vinculará a sus respuestas a la encuesta.

Los investigadores utilizarán sus datos para realizar este estudio. Una vez finalizado el estudio con sus datos, podremos compartirlos con otros investigadores para que puedan utilizarlos en otros estudios en el futuro. No compartiremos su nombre ni ningún otro dato privado identificable que permita a los investigadores saber quién es usted. No le pediremos permiso adicional para compartir esta información anónima.

¿Tiene alguna pregunta? Si tiene algún comentario, duda o pregunta sobre este estudio, póngase en contacto con los investigadores que figuran en la parte superior de este formulario.

Si tiene alguna pregunta o duda sobre sus derechos como participante en una investigación, puede ponerse en contacto con la Junta de Revisión Institucional de UCI por teléfono, (949) 824-8170, por correo electrónico a IRB@research.uci.edu o en 160 Aldrich Hall, Irvine, CA 92697-7600.

¿Qué es un IRB? Una Junta de Revisión Institucional, o Institutional Review Board (IRB) en inglés, es un comité formado por científicos y no científicos. La función de la IRB es proteger los derechos y el bienestar de los seres humanos que participan en la investigación. La IRB también se asegura de que la investigación cumpla con las regulaciones, leyes y políticas institucionales aplicables.

Si desea participar en este estudio, haga clic en el botón "Aceptar" para iniciar la encuesta.

Study Information Sheet- Vietnamese

University of California, Irvine
Giấy thông tin về thí nghiệm

Đánh giá tác động của chủng tộc của nhà cung cấp-bệnh nhân và sự phù hợp về ngôn ngữ đối với kiến thức và thái độ của các nhóm dân số ít được đại diện đối với tư vấn gen di truyền

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Vui lòng đọc thông tin bên dưới. Vui lòng gửi email cho một trong những nhà nghiên cứu được liệt kê ở trên nếu có bất cứ điều gì bạn không hiểu, và chúng tôi sẽ sẵn sàng trả lời các câu hỏi của bạn.

Bạn đang được yêu cầu tham gia vào một nghiên cứu. Sự tham gia vào nghiên cứu này là tình nguyện. Bạn có thể chọn bỏ qua câu hỏi hoặc quy trình nghiên cứu. Bạn có thể từ chối tham gia hoặc ngừng tham gia bất cứ lúc nào mà không bị phạt hoặc mất lợi ích. Bạn có quyền rút khỏi nghiên cứu này bất cứ lúc nào. **Nếu bạn quyết định rút khỏi nghiên cứu này, bạn nên thông báo ngay cho nhóm nghiên cứu**.

Chúng tôi muốn bạn hoàn thành một cuộc khảo sát ẩn danh để chúng tôi có thể tìm hiểu thêm về cách các cá nhân từ các nhóm dân cư khác nhau tìm hiểu về gen di truyền và tư vấn gen di truyền. Bạn sẽ được hỏi một loạt câu hỏi, sau đó xem một đoạn video thông tin ngắn, và sau đó trả lời thêm một số câu hỏi. Toàn bộ cuộc khảo sát sẽ kéo dài khoảng 20 phút.

Những rủi ro/khó chịu có thể xảy ra liên quan đến nghiên cứu là một sự xâm phạm quyền riêng tư của bạn và có khả năng vi phạm tính bảo mật.

Tuy nhiên, tất cả dữ liệu nghiên cứu thu thập được sẽ được lưu trữ an toàn và bảo mật. Nó sẽ được duy trì dưới dạng điện tử và sẽ được bảo vệ bằng mật khẩu cũng như duy trì ở định dạng được mã hóa.

Sẽ không có lợi ích trực tiếp từ việc tham gia nghiên cứu. Tuy nhiên, những người tham gia hoàn thành cuộc khảo sát sẽ được tìm hiểu về gen di truyền, tư vấn gen di truyền và cách họ có thể tìm hiểu thêm về sức khỏe gia đình mình.

Bạn sẽ có thể tham gia xổ số để nhận một trong 10 thẻ quà tặng trị giá $25 khi tham gia vào nghiên cứu này. Người chiến thắng có thể chọn giữa thẻ quà tặng cho Amazon, Target hoặc Starbucks. Việc tham gia xổ số là tự nguyện và tách biệt với việc tham gia khảo sát. Nếu bạn chọn tham gia xổ số, một liên kết sẽ được cung cấp để bạn để lại địa chỉ email của bạn. Những phản hồi này sẽ được lưu trữ riêng biệt với các phản hồi khảo sát và địa chỉ email của bạn sẽ không được liên kết với các phản hồi khảo sát của bạn.

Các nhà nghiên cứu sẽ sử dụng thông tin của bạn để thực hiện nghiên cứu này. Sau khi nghiên cứu được thực hiện bằng cách sử dụng thông tin của bạn, chúng tôi có thể chia sẻ chúng với các nhà nghiên cứu khác để họ có thể sử dụng chúng cho các nghiên cứu

khác trong tương lai. Chúng tôi sẽ không chia sẻ tên của bạn hoặc bất kỳ thông tin nhận dạng riêng tư nào khác có thể cho các nhà nghiên cứu biết bạn là ai. Chúng tôi sẽ không yêu cầu bạn cấp thêm quyền để chia sẻ thông tin không được xác định danh tính này.

Câu hỏi? Nếu bạn có bất kỳ nhận xét, quan ngại, hoặc câu hỏi nào liên quan đến nghiên cứu này, vui lòng liên hệ với các nhà nghiên cứu được liệt kê ở đầu trang này.

Nếu bạn có thắc mắc hoặc quan ngại về quyền của mình với tư cách là người tham gia nghiên cứu, bạn có thể liên hệ UCI Institutional Review Board bằng số điện thoại, (949) 824-8170, hoặc bằng e-mail, IRB@research.uci.edu hoặc tại 160 Aldrich Hall, Irvine, CA 92697-7600.
mailto:IRB@research.uci.edu
IRB Review Board (IRB) là một ủy ban bao gồm các nhà khoa học và những người không phải là nhà khoa học. Vai trò của IRB là bảo vệ quyền và phúc lợi của các đối tượng con người tham gia nghiên cứu. IRB cũng đảm bảo rằng nghiên cứu tuân thủ các quy định, luật pháp và chính sách thể chế hiện hành.

Nếu bạn muốn tham gia vào nghiên cứu này, hãy nhấp vào nút "đồng ý" để bắt đầu khảo sát.

Appendix E: Anonymous Online Survey in English, Spanish, and Vietnamese

Page 1- Language:

In which language are you most comfortable communicating? (native language)

A. English
C. Español
D. Tiếng Việt

Page 2- Demographics:

What terms best express how you describe your gender identity? (Check all that apply)

A. Female
B. Male
C. Non-Binary
D. Gender Queer
E. Transgender
F. I prefer to self-describe: [free answer]
G. I prefer not to answer

What is your age in years today?

A. Younger than 30
B. 30-39
C. 40-49
D. 50-59
E. 60-69
F. 70 or older

Which categories describe you? Select all that apply. Note, you may select more than one group.

A. **American Indian or Alaska Native** (For example: Aztec, Blackfeet Tribe, Mayan, Navajo Nation)
B. **Asian** (For example: Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, etc.)
C. **Black, African American, or African** (For example: African American, Ethiopian, Haitian, Jamaican, Nigerian, Somali, etc.)
D. **Hispanic, Latino** (For example: Colombian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadoran, etc.)
E. **Middle Eastern or North African** (For example: Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian, etc.)
F. **Native Hawaiian or other Pacific Islander** (For example: Chamorro, Fijian, Marshallese, Native Hawaiian, Tongan, etc.)
G. **White** (For example: European, French, German, Irish, Italian, Polish, Spanish, etc.)
H. Other [free answer]

A. I was born in the United States.

B. I was born outside of the United States.

Please enter the zip code where your primary home is located: (this information is being gathered only to identify access to genetic services by location) [free answer]

What is the highest grade or year of school you completed?

A. Elementary (up to grade 8) or less
B. High school graduate or GED or less
C. Some College or technical school (1 - 3 years)
D. College graduate (4 years or more)
E. Graduate degree (Masters, MD, PhD, etc.)

What is your annual household income from all sources?
A. $19,999 or less
B. $20,000- $49,999
C.$50,000 -$99,999
D. $100,000- 149,999
E. $150,000 or more
F. I prefer not to answer

Which of the following options best describes your religious affiliation? (select all that apply)

A. Buddhist
C. Christian
D. Hindu
D. Jewish
E. Muslim
F. I prefer to self-describe: [free answer]
G. No affiliation
H. I prefer not to answer

Are you covered by health insurance? [Yes or no]

If yes:
I have:

A. a plan purchased through an employer or union (including plans purchased through another person's employer)
B. a private nongovernmental plan that I or another family member buys on their own
C. a government-provided insurance plan such as Medicare, Medicaid, Medical, Medigap, or CHIP
D. Military related health care (TRICARE, CHAMPUS)
E. a plan through Indian Health Service

Page 3- Understanding of Biology and Genetics:

[strongly agree, agree, disagree, strongly disagree]

I can briefly explain:

1. what DNA is.
2. what genes are.
3. what chromosomes are.
4. how changes in genes or chromosomes can result in disease.
5. how tests can detect changes in our genes.

Page 4- Awareness of Genetic Counseling:

Have you ever heard of a healthcare provider called a genetic counselor? [yes or no]

If no: Genetic counselors are health care providers who can help you understand genetic conditions that could affect your health and your family's health, such as your children or future children. [move to page 5]

If yes: have you ever received genetic counseling services? [yes or no]

If yes or no: Genetic counselors are health care providers who can help you understand genetic conditions that could affect your health and your family's health, such as your children or future children.

Page 5- Understanding of Genetic Counseling:

[True, False, I do not know]

1. Medical information received from an at-home DNA or ancestry kit (such as ancestry.com, 23andme, or similar) is the same as results from a clinical genetic test ordered by a Genetic Counselor. [False]
2. Genetic counseling is available to people who are planning to become pregnant. [True]
3. When someone has an illness (like cancer), genetic test results can help their doctors choose an appropriate treatment. [True]
4. When a genetic condition is found in a fetus, a Genetic Counselor will recommend an abortion (or termination of the pregnancy). [False]
5. Genetic Counselors help people choose desirable traits for their future children such as height, hair color, and intelligence. [False]
6. You can see a Genetic Counselor even if no one in your family has ever had a genetic (inherited) condition. [True]
7. Genetic counseling is only available to women who are pregnant. [False]
8. Genetic Counselors can change a person's genetic makeup. [False]
9. People who are adopted or have limited information about their blood relatives can benefit from genetic counseling. [True]
10. People who are not interested in genetic testing can still benefit from talking to a genetic counselor. [True]

Page 6: Attitudes regarding Genetic Counseling:
[strongly agree, agree, disagree, strongly disagree]

1. I am afraid of my child or myself receiving a genetic diagnosis from a Genetic Counselor.
2. I know how to get connected with a Genetic Counselor.
3. I am confident that my conversations with my Genetic Counselor will be kept private. (Including from my employer, health insurance company, and other family members who see the same provider.)
4. I believe that Genetic Counseling can benefit at least one of my blood family members (parents, siblings, grandparents, aunts, uncles, and/or cousins)
5. Genetic counseling is something that I <u>can</u> afford.
6. It is important to me that my genetic counselor has a similar cultural identity as me. (race/identity)
7. I feel only genetic counselors who share my race or ethnicity can fully understand the cultural undertones behind some of my decisions.
8. I believe genetic counselors who share my race or ethnicity can facilitate a more inclusive experience for me.
9. It is important to me that my genetic counselor can speak the same language as me without the use of a translator.
10. I think I would feel comfortable making a decision about genetic testing after speaking with a Genetic Counselor.

Page 7: Video From Genetic Counselor
Page 8: repeat page 3
Page 9: Repeat page 5
Page 10: Repeat page 6

Anonymous Online Survey- Spanish

Página 1- Idioma:

¿En qué idioma te sientes más cómodo comunicándote? (idioma nativo)

B. Inglés [go to English Survey]
B. Español [go to Spanish Survey]
E. Vietnamita (Tiếng Việt) [go to Vietnamese Survey]

Página 2- Demografía:

¿Qué términos expresan mejor cómo describes tu identidad en cuestión de género? (Marque todo lo que corresponda)

B. Femenino
C. Masculino
D. No binario
E. Género Queer
F. Transgénero
G. Prefiero autodescribirme: [free answer]
H. Prefiero no contestar

¿Cuál es tu edad (en años) hoy?

G. Menos de 30 años de edad
H. 30-39 años de edad
I. 40-49 años de edad
J. 50-59 años de edad
K. 60-69 años de edad
L. 70 años de edad o más

¿Cuál de estas categorías te describe? Seleccione todas las que correspondan. Tenga en cuenta que puede seleccionar más de un grupo.

B. **Indio americano o nativo de Alaska** (por ejemplo: azteca, tribu de los pies negros, maya, nación navajo)
C. **Asiático** (por ejemplo: indio asiático, chino, filipino, japonés, coreano, vietnamita, etc.)
D. **Negro, afroamericano o africano** (por ejemplo: afroamericano, etíope, haitiano, jamaicano, nigeriano, somalí, etc.)
E. **Hispano(a), Latino(a)(e)** (Por ejemplo: colombiano, cubano, dominicano, mexicano o mexicoamericano, puertorriqueño, salvadoreño, etc.)
F. **Oriente Medio o norte de África** (por ejemplo: argelino, egipcio, iraní, libanés, marroquí, sirio, etc.)
G. **Nativo de Hawái o otras islas del Pacífico** (por ejemplo: chamorro, fiyiano, marshallés, nativo de Hawái, tongano, etc.)
H. **Blanco** (Por ejemplo: inglés, europeo, francés, alemán, irlandés, italiano, polaco, originario de España, etc.)
I. Otro [free answer]

C. Yo nací en los Estados Unidos.

D. Yo nací afuera de los Estados Unidos.

Ingrese el código postal donde se encuentra su hogar principal: (esta información se está coleccionando solo para identificar el acceso a los servicios genéticos por ubicación) [free answer]

¿Cuál es el grado o año escolar más alto que ha completado?

F. Primaria (hasta 8º grado) o menos
G. Graduado de la escuela secundaria/preparatoria o GED o menos
H. Algo de universidad/colegio o escuela técnica (1 - 3 años)
I. Graduado de la universidad (4 años o más)
J. Título de posgrado (maestría, título de medicina, doctorado, etc.)

¿Cuál es su ingreso familiar anual de todas sus fuentes de ingreso?

A. $19,999 o menos
B. $20,000- $49,999
C.$50,000 -$99,999
D. $100,000- 149,999
E. $150,000 o más
F. Prefiero no contestar

¿Cuál de las siguientes opciones describe mejor su afiliación religiosa? (seleccione todas las que correspondan)

B. Budista
B. Cristiano(a)
E. Hindú
E. Judío
F. Musulmán
G. Prefiero autodescribirme: [free answer]
H. Sin afiliación religiosa
I. Prefiero no contestar

¿Está cubierto por un seguro médico o algún otro tipo de plan de atención médica? [Yes or no]

If yes:

Yo tengo:

A. Un plan comprado a través de un empleador o sindicato (incluidos los planes comprados a través del empleador de otra persona)
C. Un plan privado no gubernamental que yo u otro miembro de mi familia compra por su cuenta
D. Un plan de seguro médico proporcionado por el gobierno, como Medicare, Medicaid, Medical, Medigap o CHIP

E. Un plan de atención médica relacionada con las Fuerzas Armadas (TRICARE, CHAMPUS)
F. Un plan a través del Servicio de Salud Indígena

Página 3- Comprensión de la Biología y la Genética:

[strongly agree, agree, disagree, strongly disagree]

Yo puedo explicar brevemente:

2. qué es el ADN.
3. qué son los genes.
4. qué son las cromosomas.
5. cómo los cambios en los genes o las cromosomas pueden causar enfermedades.
6. cómo las pruebas pueden detectar cambios en nuestros genes.

Página 4- Conocimiento del Asesoramiento Genético:

¿Alguna vez ha oído hablar de un proveedor de salud médico llamado un asesor genético o asesora genética?

If no: Los asesores genéticos/las asesoras genéticas son proveedores de salud médica que pueden ayudarle a comprender las condiciones genéticas que podrían afectar su salud y la de su familia, como la de sus hijos(as) o futuros hijos(as). [move to page 5]

If yes: ¿alguna vez ha recibido servicios de asesoramiento genético? [yes or no]

If yes or no: Los asesores genéticos/las asesoras genéticas son proveedores de salud médica que pueden ayudarle a comprender las condiciones genéticas que podrían afectar su salud y la de su familia, como la de sus hijos(as) o futuros hijos(as).

Página 5- Comprensión del Asesoramiento Genético:

[True, False, I do not know]

11. La información médica recibida de un kit casero mandado a mi hogar que utiliza mi ADN para cuestiones de salud o ascendencia ancestral (como ancestry.com, 23andme o compañía similar) es la misma que los resultados de una prueba genética clínica ordenada por un asesor genético/asesora genética. [False]
12. El asesoramiento genético está disponible para las personas que planean tener un embarazo. [True]
13. Cuando alguien tiene una enfermedad (como el cáncer), los resultados de las pruebas genéticas pueden ayudar a los doctores de esa persona a elegir un tratamiento adecuado. [True]

14. Cuando se encuentra una condición genética en un feto, un asesor genético/una asesora genética recomendará un aborto (o la interrupción/finalización prematura del embarazo). [False]
15. Los asesores genéticos/asesoras genéticas ayudan a las personas a elegir características deseables para sus futuros hijos(as), como la altura, el color de cabello y la inteligencia. [False]
16. Puede consultar a un asesor genético/asesora genética incluso si nadie en su familia ha tenido una condición genética (hereditaria). [True]
17. El asesoramiento genético solo está disponible para mujeres embarazadas. [False]
18. Los asesores genéticos/asesoras genéticas pueden cambiar la composición genética o genes de una persona. [False]
19. Las personas que son adoptadas o tienen información limitada sobre sus familiares de sangre pueden beneficiarse del asesoramiento genético. [True]
20. Las personas que no están interesadas en las pruebas genéticas todavía pueden beneficiarse de hablar con un asesor genético/asesora genética. [True]

Page 6: Actitudes Con Respecto Al Asesoramiento Genético:

[strongly agree, agree, disagree, strongly disagree]

11. Tengo miedo de que mi hijo(a) o yo recibamos un diagnóstico de una condición genética de un asesor genético/una asesora genética.
12. Sé cómo ponerme en contacto con un asesor genético/una asesora genética.
13. Estoy seguro de que mis conversaciones con mi asesor genético/asesora genética se mantendrá en privado. (Incluyendo de mi empleador, compañía de seguro médico o de salud y otros miembros de la familia que ven al mismo proveedor de salud).
14. Creo que el asesoramiento genético puede beneficiar al menos a uno de los miembros de mi familia de sangre (padres, hermanos/hermanas, abuelos/abuelas, tías, tíos y/o primos/primas).
15. El asesoramiento genético es algo que puedo pagar.
16. Es importante para mí que mi asesor genético/asesora genética tenga una identidad cultural similar a la mía. (raza/identidad).
17. Siento que solo los asesores genéticos/asesoras genéticas que comparten mi raza o grupo étnico pueden comprender completamente los matices culturales detrás de algunas de mis decisiones relacionados a mi salud.
18. Creo que los asesores genéticos/asesoras genéticas que comparten mi raza o grupo étnico pueden facilitarme una experiencia más inclusiva para mí.
19. Es importante para mí que mi asesor genético/asesora genética pueda hablar el mismo idioma que yo sin el uso de un intérprete médico.
20. Creo que me sentiría cómodo(a) tomando una decisión sobre las pruebas genéticas después de hablar con un asesor genético/asesora genética.

Anonymous Online Survey- Vietnamese

Page 1 – Ngôn ngữ

Ngôn ngữ nào sau đây khiến bạn thoải mái nhất khi giao tiếp (tiếng mẹ đẻ)

A. Tiếng anh
B. Tiếng Tây Ban Nha
C. Tiếng Việt

Page 2 – Thông tin cá nhân

Từ nào sau đây thể hiện chính xác nhất cách bạn miêu tả giới tính của mình? (Chọn tất cả những từ áp dụng với bạn)

A. Nữ
B. Nam
C. Song tính
D. Không có giới tính xác định
E. Người chuyển giới
F. Tôi muốn tự miêu tả bản thân:
G. Tôi không muốn trả lời

Hôm nay bạn bao nhiêu tuổi tính theo năm?

A. Nhỏ hơn 30 tuổi
B. 30-39
C. 40-49
D. 50-59
E. 60-69
F. 70 tuổi hoặc lớn hơn

Sự phân loại nào dưới đây miêu tả bạn? Chọn tất cả những câu áp dụng với bạn. Chú ý, bạn có thể lựa chọn nhiều hơn một nhóm.

A. Người Mỹ gốc Ấn Độ hoặc người bản địa Alaska (Ví dụ: người Aztec, Bộ lạc chân đen, người Maya, người quốc gia Navajo)
B. Người Châu Á (Ví dụ: người Châu Á gốc Ấn Độ, người Trung Quốc, người Philipine, người Nhật Bản, người Hàn Quốc, người Việt Nam, vân vân.)
C. Người da đen, người Mỹ gốc Phi, hoặc người Châu Phi (Ví dụ: người Mỹ gốc Phi, người Ethiopia, người Haiti, người Jamaica, người Nigeria, người Somali, vân vân.)
D. Người Tây Ban Nha, người La Tinh (Ví dụ: người Colombia, người Cuba, người Dominica, người Mexico hoặc người Mỹ gốc Mexico, người Puerto Rico, người Salvador, vân vân.)

E. Người Trung Đông hoặc người Bắc Phi (Ví dụ: người Algeria, người Ai Cập, người Iran, người Lebanon, người Morocco, người Syria, vân vân.)
F. Người bản địa Hawaii hoặc người dân đảo Thái Bình Dương khác (Ví dụ: người Chamorro, người Fiji, người Marshall, người bản địa Hawaii, người Tongan, vân vân.)
G. Người da trắng (Ví dụ: người Châu Âu, người Pháp, người Đức, người Ireland, người Ý, người Ba Lan, người Tây Ban Nha, vân vân.)
H. Khác

A. Tôi được sinh ra ở Mỹ
B. Tôi được sinh ra ở ngoài nước Mỹ

Vui lòng nhập mã zip code nơi ngôi nhà hiện tại của bạn đang toạ lạc: (thông tin này được thu thập chỉ để xác định sự truy cập vào các dịch vụ về gen di truyền theo địa điểm)

Lớp hoặc năm học cao nhất bạn đã hoàn thành là gì?

A. Tiểu học (đến lớp 8) hoặc nhỏ hơn
B. Tốt nghiệp trung học hoặc có chứng chỉ GED hoặc ít hơn
C. Học đại học hoặc trường kĩ thuật (1-3 năm)
D. Tốt nghiệp đại học (4 năm hoặc hơn)
E. Bằng cao học (thạc sĩ, bác sĩ, tiến sĩ, vân vân.)

Thu nhập hằng năm của nhà bạn từ tất cả các nguồn là bao nhiêu?

A. $19,999 hoặc ít hơn
B. $20,000- $49,999
C. $50,000 -$99,999
D. $100,000- 149,999
E. $150,000 hoặc nhiều hơn
F. Tôi không muốn trả lời

Sự lựa chọn nào sau đây miêu tả chính xác nhất tín ngưỡng tôn giáo của bạn? (Chọn tất cả những lựa chọn áp dụng với bạn)

A. Đạo Phật
B. Đạo Tin Lành
C. Đạo Hindu
D. Đạo Do Thái
E. Đạo Hồi giáo
F. Tôi muốn tự miêu tả:
G. Không có tín ngưỡng nào

H. Tôi không muốn trả lời

Bạn có được bảo hiểm y tế chi trả không?

Tôi có:

A. Kế hoạch bảo hiểm mua qua nơi làm việc hoặc tổ chức (bao gồm kế hoạch mua qua nơi làm việc của người khác)
B. Kế hoạch bảo hiểm tư nhân không liên quan đến chính phủ mà tôi hoặc người nhà của tôi mua cho mình
C. Kế hoạch bảo hiểm mà chính phủ cung cấp như là Medicare, Medicaid, Medical, Medigap, hoặc CHIP
D. Dịch vụ chăm sóc sức khoẻ liên quan đến quân đội (TRICARE, CHAMPUS)
E. Kế hoạch bảo hiểm thông qua dịch vụ sức khoẻ của Ấn Độ

Page 3 – Sự hiểu biết về Sinh học và Gen di truyền

Tôi có thể giải thích sơ qua:

1. DNA là gì.
2. Gen là gì.
3. Nhiễm sắc thể là gì.
4. Sự thay đổi ở gen hoặc nhiễm sắc thể có thể dẫn đến bệnh tật như thế nào.
5. Làm thế nào để các xét nghiệm có thể phát hiện ra sự thay đổi ở gen của chúng ta.

Page 4 - Sự nhận biết về tư vấn gen di truyền

Bạn có bao giờ nghe về nhà cung cấp dịch vụ chăm sóc sức khoẻ gọi là chuyên gia tư vấn gen di truyền chưa?

Nếu chưa: Chuyên gia tư vấn gen di truyền là những người cung cấp dịch vụ chăm sóc sức khoẻ có thể giúp bạn hiểu về những tình trạng gen di truyền có thể ảnh hưởng đến sức khoẻ của bạn và sức khoẻ của gia đình bạn, như là con của bạn hoặc con tương lai của bạn.

Nếu có: bạn có tiếp nhận dịch vụ tư vấn gen di truyền bao giờ chưa?

Nếu có hoặc chưa: Chuyên gia tư vấn gen di truyền là những người cung cấp dịch vụ chăm sóc sức khoẻ có thể giúp bạn hiểu về những tình trạng gen di truyền có thể ảnh hưởng

đến sức khoẻ của bạn và sức khoẻ của gia đình bạn, như là con của bạn hoặc con tương lai của bạn.

Page 5 - Sự hiểu biết về tư vấn gen di truyền:

1. Thông tin y tế nhận được từ bộ dụng cụ kiểm tra DNA hoặc tổ tiên tại nhà (như là ancestry.com, 23andme, hoặc tương tự như vậy) giống với kết quả từ xét nghiệm gen di truyền lâm sàng được yêu cầu bởi chuyên gia tư vấn gen di truyền.
2. Tư vấn gen di truyền có thể được cung cấp cho những người đang có dự định mang thai.
3. Khi một người bị bệnh (như là ung thư), kết quả xét nghiệm gen có thể giúp bác sĩ của họ lựa chọn cách điều trị phù hợp.
4. Khi tình trạng di truyền được tìm thấy ở thai nhi, chuyên gia tư vấn di truyền sẽ khuyến khích phá thai (hoặc chấm dứt thai kỳ).
5. Chuyên gia tư vấn gen di truyền giúp mọi người lựa chọn những đặc điểm mong muốn cho con tương lai của họ như là chiều cao, màu tóc, và trí thông minh.
6. Bạn có thể gặp chuyên gia tư vấn gen di truyền ngay cả khi nếu không ai trong gia đình bạn từng có tình trạng gen (di truyền).
7. Tư vấn gen di truyền chỉ được cung cấp cho phụ nữ đang mang thai.
8. Chuyên gia tư vấn gen di truyền có thể thay đổi cấu trúc gen của một người.
9. Những người được nhận nuôi hoặc có hạn chế thông tin về người thân máu mủ có thể có lợi từ tư vấn gen di truyền.
10. Những người không cảm thấy hứng thú với xét nghiệm gen vẫn có thể có lợi từ việc nói chuyện với chuyên gia tư vấn gen di truyền.

Page 6 – Thái độ về tư vấn gen di truyền

1. Tôi sợ rằng con tôi hoặc tôi nhận được chẩn đoán gen di truyền từ chuyên gia tư vấn gen di truyền.
2. Tôi biết làm thế nào để kết nối với chuyên gia tư vấn gen di truyền
3. Tôi tự tin là cuộc hội thoại của tôi với chuyên gia tư vấn gen di truyền sẽ được giữ bảo mật. (bao gồm khỏi chỗ làm của tôi, công ty bảo hiểm của tôi, và cả những thành viên khác trong gia đình tôi đến khám cùng một chuyên gia.)
4. Tôi tin là tư vấn gen di truyền có thể có lợi với ít nhất một trong những người thân máu mủ của tôi (ba mẹ, anh chị em ruột, ông bà, cô dì, chú bác, và/hoặc anh chị em họ)
5. Tư vấn gen di truyền là thứ mà tôi có thể chi trả được.
6. Rất là quan trọng với tôi nếu chuyên gia tư vấn gen di truyền của tôi có cùng một nền văn hoá với tôi (chủng tộc/danh tính)

7. Tôi cảm thấy chỉ có những chuyên gia tư vấn gen di truyền chia sẻ cùng một chủng tộc hoặc sắc tộc với tôi mới có thể hiểu đầy đủ những nền tảng văn hoá đằng sau những quyết định của tôi.
8. Tôi tin là những chuyên gia tư vấn gen di truyền chia sẻ cùng một chủng tộc hoặc sắc tộc với tôi có thể tạo điều kiện cho tôi có một trải nghiệm hoà nhập hơn.
9. Rất là quan trọng với tôi nếu chuyên gia tư vấn gen di truyền của tôi có thể nói cùng một ngôn ngữ với tôi mà không cần dùng đến người phiên dịch.
10. Tôi nghĩ tôi sẽ cảm thấy thoải mái đưa ra quyết định về việc xét nghiệm gen di truyền sau khi nói chuyện với chuyên gia tư vấn gen di truyền.

Appendix F: Back Translation of Survey- Spanish

Page 1 – Language

In which language do you feel the most comfortable communicating? (Native language)

A. English [Go to English Survey]
B. Español [Go to Spanish Survey]
C. Vietnamita (Tiếng Việt) [go to Vietnamese Survey]

Page 2 – Demographics

Which terms best express how you describe your gender identity? (Mark all that corresponds)

A. Feminine
B. Masculine
C. Non-binary
D. Gender queer
E. Transgender
F. I would prefer to describe myself: [free answer]
G. Prefer not to respond

What is your age (in years) today?

A. Less than 30 years old
B. 30-39 years old
C. 40-49 years old
D. 50-59 years old
E. 60-69 years old
F. 70 years old or more

Which categories describe you? Choose all that correspond. Keep in mind that more than one group can be selected.

C. **Native American or Alaska Native** (For example: Aztec, Tribe of the Black Feet, Maya, Navajo Nation)
D. **Asian** (For example: Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, etc.)
E. **Black, African-American, or African** (For example: African-American, Ethiopian, Haitian, Jamaican, Nigerian, Somali, etc.)
F. **Hispanic, Latino(a)(e)** (For example: Colombian, Cuban, Dominican, Mexican or Mexican-American, Puerto Rican, Salvadorian, etc.)
G. **Middle-Eastern or North African** (For example: Algerian, Egyptian, Iranian, Lebanese, Morrocan, Syrian, etc.)
H. **Native Hawaiian or Pacific Islander** (For example: Chamorro, Fiyiano, Marshallese, Native of Hawaii, Tongan, etc.)
I. **White** (For example: English, European, French, German, Irish, Italian, Polish, Spanish, etc.)
J. Other [Free Answer]

A. I was born in the United States
B. I was born outside of the United States

Enter the zip code of your primary residence: (this information is collected only to identify access to genetic services by location) [free answer]

What is the highest grade or school year that you have completed?
A. Primary school (up to 8th grade) or less
B. Graduated high school/preparatory school or GED or less
C. Some university/college or technical school (1-3 years)
D. University/college graduate (4 years or more)
E. Post-graduate title (masters, medical doctorate, doctorate, etc)

What is your annual income from all of your sources of income?
A. $19,999 or less
B. $20,000 - $49,999
C.$50,000 - $99,999
D. $100,000 - 149,999
E. $150,000 or more
F. Prefer not to answer

Which of the following options best describe your religious affiliation? (Select all that correspond)
A. Buddhist
B. Christian
C. Hindu
D. Jewish
E. Muslim
F. Prefer to describe myself: [free text]
G. Without religious affiliation
H. Prefer not to answer

Are you covered by medical insurance or other type of medical attention plan? [Yes or no]

If yes,
I have:

A. A plan bought through an employer or labor union (includes plans bought through the employer of another person)
B. A private plan, not from the government, that I and another member of my family buy for myself or ourselves
C. A medical insurance plan proportioned from the government, like Medicare, Medicaid, MediCal, Medigap, or CHIP
D. A medical care plan related to the Armed Forces (TRICARE, CHAMPUS)
E. A plan through the Indian Health Service

Page 3 – Comprehension of Biology and Genetics

[strongly agree, agree, disagree, strongly disagree]

I can briefly explain:

1. What DNA is
2. What genes are
3. What chromosomes are
4. How changes in genes or chromosomes can cause diseases
5. How tests can detect changes in our genes

Page 4 – Knowledge of Genetic Counseling

Have you ever heard of a medical health provider called a genetic counselor?

> If not: Genetic counselors are providers of health care that can help you understand the genetic conditions that could affect your health and that of your family, like that of your children or your future children. [move to page 5]
>
> If yes: Have you ever received genetic counseling services? [yes or no]
>
> If yes or no: Genetic counselors are providers of health care that can help you understand the genetic conditions that could affect your health and that of your family, like that of your children or your future children.

Page 5 – Understanding of Genetic Counseling

[True, False, I do not know]

1. The medical information received from a home kit sent to my home that uses my DNA for health issues or ancestral ancestry (like ancestry.com, 23andme or a similar company) is the same as the results of clinical genetic test ordered by a genetic counselor. [False]
2. Genetic counselors are available for people who plan to have a pregnancy. [True]
3. When someone has an illness (like cancer), the results of genetic tests can help the doctors of that person choose an appropriate treatment. [True]
4. When a genetic condition is found in a fetus, a genetic counselor recommends an abortion (or the premature interruption/finalization of the pregnancy). [False]
5. Genetic counselors help people choose desirable characteristics for their future children, like height, hair color, and intelligence. [False]
6. You can consult a genetic counselor even if no one in your family has a genetic condition (hereditary). [True]
7. Genetic counseling is only available for pregnant women. [False]
8. Genetic counselors can change the genetic composition or the genes of a person. [False]

9. People who are adopted or have limited information about their blood-related families can benefit from genetic counseling. [True]
10. People who are not interested in genetic testing can still benefit from talking to a genetic counselor. [True]

Page 6 - Attitudes About Genetic Counseling

[strongly agree, agree, disagree, strongly disagree]

1. I'm afraid that my child or I will receive a diagnosis of a genetic condition from a genetic counselor.
2. I know how to get in contact with a genetic counselor.
3. I'm sure that my conversations with my genetic counselor will remain private. (Including from my employer, health insurance company, and other members of my family who see the same health provider).
4. I believe that genetic counseling can help at least one member of my blood-related family (parents, siblings, grandparents, aunts, uncles, cousins).
5. Genetic counseling is something I can afford.
6. It is important to me that my genetic counselor has a cultural identity similar to mine (race/identity).
7. I feel that only genetic counselors that share my race or ethnic group can completely understand the cultural nuance behind some of my decisions related to my health.
8. I believe that genetic counselors that share my race or ethnicity can make it easier for me to have a more inclusive experience.
9. It is important to me that my genetic counselor can speak the same language as me without the use of a medical interpreter.
10. I believe that I would feel comfortable making a decision about genetic tests after talking to a genetic counselor.

Appendix F: Back Translation of Survey- Vietnamese

Page 1 – Ngôn ngữ
Ngôn ngữ nào sau đây khiến bạn thoải mái nhất khi giao tiếp (tiếng mẹ đẻ)

D. Tiếng anh
E. Tiếng Tây Ban Nha
F. Tiếng Việt

Page 1 – Language
Which of the following languages makes you most comfortable when communicating (native language)

A. English
B. Spanish
C. Vietnamese

Page 2 – Thông tin cá nhân
Từ nào sau đây thể hiện chính xác nhất cách bạn miêu tả giới tính của mình? (Chọn tất cả những từ áp dụng với bạn)

Nữ
Nam
Song tính
Không có giới tính xác định
Người chuyển giới
Tôi muốn tự miêu tả bản thân:
Tôi không muốn trả lời

Page 2 – Personal information
Which of the following terms appears to best describe your gender?
(Choose all the terms that apply to you)

A. Male
B. Female
C. Non-binary
D. Gender queer
E. Transgender
F. I want to self-describe:
G. I do not want to answer

Hôm nay bạn bao nhiêu tuổi tính theo năm?

Nhỏ hơn 30 tuổi
30-39

40-49
50-59
60-69
70 tuổi hoặc lớn hơn

How old are you, in years, today?

A. Less than 30
B. 30-39
C. 40-49
D. 50-59
E. 60-69
F. 70 or older

Sự phân loại nào dưới đây miêu tả bạn? Chọn tất cả những câu áp dụng với bạn. Chú ý, bạn có thể lựa chọn nhiều hơn một nhóm.

Người Mỹ gốc Ấn Độ hoặc người bản địa Alaska (Ví dụ: người Aztec, Bộ lạc chân đen, người Maya, người quốc gia Navajo)
Người Châu Á (Ví dụ: người Châu Á gốc Ấn Độ, người Trung Quốc, người Philipine, người Nhật Bản, người Hàn Quốc, người Việt Nam, vân vân.)
Người da đen, người Mỹ gốc Phi, hoặc người Châu Phi (Ví dụ: người Mỹ gốc Phi, người Ethiopia, người Haiti, người Jamaica, người Nigeria, người Somali, vân vân.)
Người Tây Ban Nha, người La Tinh (Ví dụ: người Colombia, người Cuba, người Dominica, người Mexico hoặc người Mỹ gốc Mexico, người Puerto Rico, người Salvador, vân vân.)
Người Trung Đông hoặc người Bắc Phi (Ví dụ: người Algeria, người Ai Cập, người Iran, người Lebanon, người Morocco, người Syria, vân vân.)
Người bản địa Hawaii hoặc người dân đảo Thái Bình Dương khác (Ví dụ: người Chamorro, người Fiji, người Marshall, người bản địa Hawaii, người Tongan, vân vân.)
Người da trắng (Ví dụ: người Châu Âu, người Pháp, người Đức, người Ireland, người Ý, người Ba Lan, người Tây Ban Nha, vân vân.)
Khác

Which category best describes you? Choose all that apply to you. Of note, you can choose more than one grouping.

A. American Indian or Alaskan Native (Example: Aztec, Blackfeet tribe, Mayan, Navajo nation)
B. Asian (Example: Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, etc.)

C. Black, African American, or African (Example: African American, Ethiopian, Haitian, Jamaican, Nigerian, Somalian, etc.)
D. Spanish, Latino (Example: Colombian, Cuban, Dominican, Mexican or Mexican American, Puerto Rican, Salvadorian, etc.)
E. Middle Eastern or Northern African (Example: Algerian, Egyptian, Iranian, Lebanese, Moroccan, Syrian, etc.)
F. Hawaiian or Pacific Islander (Example: Chamorro, Fijian, Marshallese, Native Hawaiian, Tongan, etc.)
G. White (Example: European, French, German, Irish, Italian, Polish, Spanish, etc.)
H. Other

Tôi được sinh ra ở Mỹ
Tôi được sinh ra ở ngoài nước Mỹ

A. I was born in the US
B. I was born outside of the US

Vui lòng nhập mã zip code nơi ngôi nhà hiện tại của bạn đang toạ lạc: (thông tin này được thu thập chỉ để xác định sự truy cập vào các dịch vụ về gen di truyền theo địa điểm)

Please enter the zip code for your current residence: (this information is collected only to determine access regarding genetics services by location)

Lớp hoặc năm học cao nhất bạn đã hoàn thành là gì?
Tiểu học (đến lớp 8) hoặc nhỏ hơn
Tốt nghiệp trung học hoặc có chứng chỉ GED hoặc ít hơn
Học đại học hoặc trường kĩ thuật (1-3 năm)
Tốt nghiệp đại học (4 năm hoặc hơn)
Bằng cao học (thạc sĩ, bác sĩ, tiến sĩ, vân vân.)

What is the highest grade or year of school you completed?
A. Elementary (until 8th grade) or less
B. High school graduate, or have a GED, or less
C. Attended college or technical college (1-3 years)
D. College graduate (4 years or more)
E. Graduate degree (Master's, MD, PhD, etc.)

Thu nhập hằng năm của gia đình bạn từ tất cả các nguồn là bao nhiêu?

$19,999 hoặc ít hơn
$20,000- $49,999
$50,000 -$99,999
$100,000- 149,999
$150,000 hoặc nhiều hơn
Tôi không muốn trả lời

How much is your yearly income, from all sources?- make sure this means household combined income

A. $19,999 or less
B. $20,000- $49,999
C. $50,000 -$99,999
D. $100,000- 149,999
E. $150,000 or more
F. I do not want to answer

Sự lựa chọn nào sau đây miêu tả chính xác nhất tín ngưỡng tôn giáo của bạn? (Chọn tất cả những lựa chọn áp dụng với bạn)

Đạo Phật
Đạo Tin Lành
Đạo Hindu
Đạo Do Thái
Đạo Hồi giáo
Tôi muốn tự miêu tả:
Không có tín ngưỡng nào
Tôi không muốn trả lời

Which of the following options most closely describes your religious beliefs?
(Choose all of the options that apply to you)

A. Buddhism
B. Christian
C. Hindu
D. Jewish
E. Muslim
F. I want to self-describe:
G. No beliefs
H. I do not want to answer

Bạn có được bảo hiểm y tế ~~chi trả~~ không?

Do you get funded health insurance?

Tôi có:

Kế hoạch bảo hiểm mua qua nơi làm việc hoặc tổ chức (bao gồm kế hoạch mua qua nơi làm việc của người khác)
Kế hoạch bảo hiểm tư nhân không liên quan đến chính phủ mà tôi hoặc người nhà của tôi mua cho mình
Kế hoạch bảo hiểm mà chính phủ cung cấp như là Medicare, Medicaid, Medical, Medigap, hoặc CHIP
Dịch vụ chăm sóc sức khoẻ liên quan đến quân đội (TRICARE, CHAMPUS)
Kế hoạch bảo hiểm thông qua dịch vụ sức khoẻ của Ấn Độ

I have:

A. An insurance plan purchased through the workplace or union (includes an insurance plan purchased through the workplace of another person)
B. A private, non-governmental, insurance plan that I or my relative purchased for me
C. A government provided insurance plan such as Medicare, Medicaid, Medical, Medigap, or CHIP
D. Healthcare services associated with the military (TRICARE, CHAMPUS)
E. An insurance plan through Indian healthcare services

Page 3 – Sự hiểu biết về Sinh học và Gen di truyền

Tôi có thể giải thích sơ qua:

DNA là gì.
Gen là gì.
Nhiễm sắc thể là gì.
Sự thay đổi ở gen hoặc nhiễm sắc thể có thể dẫn đến bệnh tật như thế nào.
Làm thế nào để các xét nghiệm có thể phát hiện ra sự thay đổi ở gen của chúng ta.

Page 3 – Understanding of Biology and Genetics- need agree disagree

I can explain briefly:

1. What DNA is.
2. What genes are.
3. What chromosomes are.

4. How changes in genes or chromosomes can lead to disease.
5. How tests can discover changes in our genes.

Page 4 - Sự nhận biết về tư vấn gen di truyền

Bạn có bao giờ nghe về nhà cung cấp dịch vụ chăm sóc sức khoẻ gọi là chuyên gia tư vấn gen di truyền chưa?

Nếu chưa: Chuyên gia tư vấn gen di truyền là những người cung cấp dịch vụ chăm sóc sức khoẻ có thể giúp bạn hiểu về những tình trạng gen di truyền có thể ảnh hưởng đến sức khoẻ của bạn và sức khoẻ của gia đình bạn, như là con của bạn hoặc con tương lai của bạn.

Nếu có: bạn có tiếp nhận dịch vụ tư vấn gen di truyền bao giờ chưa?

Nếu có hoặc chưa: Chuyên gia tư vấn gen di truyền là những người cung cấp dịch vụ chăm sóc sức khoẻ có thể giúp bạn hiểu về những tình trạng gen di truyền có thể ảnh hưởng đến sức khoẻ của bạn và sức khoẻ của gia đình bạn, như là con của bạn hoặc con tương lai của bạn.

Page 4 – Recognition of genetic counseling

Have you ever heard of a healthcare provider called a genetic counselor before?

If no: Genetic counselors are healthcare providers who can help you understand about genetic conditions that can affect your health and your family's health, such as your children or your future children.

If yes: Have you ever received genetic counseling services before?

If yes or no: A genetic counselor are healthcare providers who can help you understand about genetic conditions that can affect your health and your family's health, such as your children or your future children.

Page 5 - Sự hiểu biết về tư vấn gen di truyền:

Thông tin y tế nhận được từ bộ dụng cụ kiểm tra DNA hoặc tổ tiên tại nhà (như là ancestry.com, 23andme, hoặc tương tự như vậy) giống với kết quả từ xét nghiệm gen di truyền lâm sàng được yêu cầu bởi chuyên gia tư vấn gen di truyền.
Tư vấn gen di truyền có thể được cung cấp cho những người đang có dự định mang thai.

Khi một người bị bệnh (như là ung thư), kết quả xét nghiệm gen có thể giúp bác sĩ của họ lựa chọn cách điều trị phù hợp.
Khi tình trạng di truyền được tìm thấy ở thai nhi, chuyên gia tư vấn di truyền sẽ khuyến khích phá thai (hoặc chấm dứt thai kỳ).
Chuyên gia tư vấn gen di truyền giúp mọi người lựa chọn những đặc điểm mong muốn cho con tương lai của họ như là chiều cao, màu tóc, và trí thông minh.
Bạn có thể gặp chuyên gia tư vấn gen di truyền ngay cả khi nếu không ai trong gia đình bạn từng có tình trạng gen (di truyền).
Tư vấn gen di truyền chỉ được cung cấp cho phụ nữ đang mang thai.
Chuyên gia tư vấn gen di truyền có thể thay đổi cấu trúc gen của một người.
Những người được nhận nuôi hoặc có hạn chế thông tin về người thân máu mủ có thể có lợi từ tư vấn gen di truyền.
Những người không cảm thấy hứng thú với xét nghiệm gen vẫn có thể có lợi từ việc nói chuyện với chuyên gia tư vấn gen di truyền.

Page 5 – Understanding of genetic counseling:

1. Medical information received from at-home genetic testing or ancestry (such as ancestry.com, 23andme, or an equivalent) is the same as results from genetic testing ordered by a genetic counselor.
2. Genetic counseling can be provided to people who are planning to become pregnant.
3. When a person is ill (such as with cancer), genetic test results can help their doctors choose the appropriate treatment.
4. When a genetic condition is identified in a fetus, a genetic counselor will advise an abortion (or termination of the pregnancy).
5. A genetic counselor helps everyone choose desired traits for their future children such as height, hair color, and intelligence.
6. You can meet a genetic counselor even if no one in your family has had a genetic condition.
7. Genetic counseling is only provided to pregnant women.
8. A genetic counselor is able to change a person's genetic makeup.
9. People who are adopted or have limited information about their blood relatives can benefit from genetic counseling.
10. People who are not interested in genetic testing can benefit from speaking with a genetic counselor.

Page 6 – Thái độ về tư vấn gen di truyền

Tôi sợ rằng con tôi hoặc tôi nhận được chẩn đoán gen di truyền từ chuyên gia tư vấn gen di truyền.

Tôi biết làm thế nào để kết nối với chuyên gia tư vấn gen di truyền
Tôi tự tin là cuộc hội thoại của tôi với chuyên gia tư vấn gen di truyền sẽ được giữ bảo mật. (bao gồm khỏi chỗ làm của tôi, công ty bảo hiểm của tôi, và cả những thành viên khác trong gia đinh tôi đến khám cùng một chuyên gia.)
Tôi tin là tư vấn gen di truyền có thể có lợi với ít nhất một trong những người thân máu mủ của tôi (ba mẹ, anh chị em ruột, ông bà, cô dì, chú bác, và/hoặc anh chị em họ)
Tư vấn gen di truyền là thứ mà tôi có thể chi trả được.
Rất là quan trọng với tôi nếu chuyên gia tư vấn gen di truyền của tôi có cùng một nền văn hoá với tôi (chủng tộc/danh tính)
Tôi cảm thấy chỉ có những chuyên gia tư vấn gen di truyền chia sẻ cùng một chủng tộc hoặc sắc tộc với tôi mới có thể hiểu đầy đủ những nền tảng văn hoá đằng sau những quyết định của tôi.
Tôi tin là những chuyên gia tư vấn gen di truyền chia sẻ cùng một chủng tộc hoặc sắc tộc với tôi có thể tạo điều kiện cho tôi có một trải nghiệm hoà nhập hơn.
Rất là quan trọng với tôi nếu chuyên gia tư vấn gen di truyền của tôi có thể nói cùng một ngôn ngữ với tôi mà không cần dùng đến người phiên dịch.
Tôi nghĩ tôi sẽ cảm thấy thoải mái đưa ra quyết định về việc xét nghiệm gen di truyền sau khi nói chuyện với chuyên gia tư vấn gen di truyền.

Page 6 – Attitudes about genetic counseling

1. I fear that my children or I could receive a genetic diagnosis from a genetic counselor.
2. I know how to connect with a genetic counselor.
3. I am confident that the conversation between a genetic counselor and me will be kept confidential. (including from my workplace, my health insurance company, and other family members who come to see the same provider.)
4. I believe that genetic counseling can be beneficial for at least one of my relatives (parents, brothers and sisters, grandparents, aunts, uncles, and/or cousins)
5. Genetic counseling is something that I can pay for.
6. It is very important to me if my genetic counselor shares a cultural background with me (race/identity).
7. I feel that only genetic counselors who share a race or ethnicity with me can fully understand the cultural background behind my decisions.
8. I believe that genetic counselors who share a race or ethnicity with me can create a more harmonious experience for me.
9. It is very important to me if my genetic counselor can speak the same language as me without needing an interpreter.
10. I think I will feel more comfortable making decisions about genetic testing after speaking with a genetic counselor.

Appendix G: Video Script- English, Spanish, and Vietnamese

Hi, my name is ____ and I am a genetic counselor. A genetic counselor is a healthcare provider trained in genetics, which is the study of our genes and how they affect our health. Genes are tiny structures in our bodies that carry instructions about how we look, grow, and stay healthy. We inherit our genes from our biological parents which is why we often look like our parents and can even have similar medical conditions.

Hola, me llamo ____ y soy asesora genética. Un asesor genético es un profesional sanitario formado en genética, que es el estudio de nuestros genes y de cómo afectan a nuestra salud. Los genes son pequeñas estructuras de nuestro cuerpo que contienen instrucciones sobre nuestro aspecto, crecimiento y salud. Heredamos los genes de nuestros padres biológicos, por lo que a menudo nos parecemos a ellos e incluso podemos padecer enfermedades similares.

Xin chào, tôi tên là ____ và tôi là một chuyên gia tư vấn gen di truyền. Một chuyên gia tư vấn gen di truyền là một nhà cung cấp dịch vụ chăm sóc sức khỏe được đào tạo về di truyền học, chuyên nghiên cứu về gen và cách chúng ảnh hưởng đến sức khỏe của chúng ta. Gen là những cấu trúc nhỏ bé trong cơ thể của chúng ta, mang theo những chỉ dẫn về việc chúng ta trông như thế nào, phát triển như thế nào, và làm thế nào để khoẻ mạnh. Chúng ta thừa hưởng gen từ cha mẹ ruột của chúng ta, đó là lý do tại sao chúng ta thường trông giống cha mẹ của mình và thậm chí có thể có các tình trạng sức khoẻ tương tự như họ.

You may have heard of DNA; it is like the instruction manual for your whole body. It's a long string of unique letters that carries all the information that makes you who you are. Genes are tiny sections of DNA. Each gene contains a unique set of instructions for a function that your body performs. We have over twenty thousand genes so to keep track of them all, our bodies organize them into larger structures called chromosomes.

Puede que hayas oído hablar del ADN: es como el manual de instrucciones de todo tu cuerpo. Es una larga cadena de letras únicas que contiene toda la información que te hace ser quien eres. Los genes son pequeñas secciones de ADN. Cada gen contiene un conjunto único de instrucciones para una función que realiza tu cuerpo. Tenemos más de veinte mil genes, por lo que, para controlarlos todos, nuestro cuerpo los organiza en estructuras más grandes llamadas cromosomas.

Bạn có thể đã nghe nói về DNA; nó giống như một cuốn sách hướng dẫn cho toàn bộ cơ thể của bạn. Đó là một chuỗi dài các chữ cái độc nhất mang tất cả thông tin tạo nên con người của bạn. Gen là những phần nhỏ của DNA. Mỗi gen chứa một bộ hướng dẫn duy nhất cho một chức năng mà cơ thể bạn thực hiện. Chúng ta có hơn hai mươi ngàn gen, vì vậy để theo dõi tất cả, cơ thể chúng ta sắp xếp chúng thành các cấu trúc lớn hơn gọi là nhiễm sắc thể.

We have two copies of every gene because we get one copy from our mother and one from our father. Changes in a gene's instruction can change how that gene performs its job. Sometimes the impact will be so small that you would never tell, like making someone one centimeter taller, and sometimes it will be something noticeable but harmless like making eyes blue instead of brown. But other times, a change in a gene can increase the risk for certain medical conditions.

Tenemos dos copias de cada gen porque recibimos una copia de nuestra madre y otra de nuestro padre. Los cambios en las instrucciones de un gen pueden alterar su funcionamiento. A veces el impacto es tan pequeño que no se nota, como que alguien sea un centímetro más alto, y a veces es algo notable pero inofensivo, como que los ojos sean azules en vez de marrones. Pero otras veces, un cambio en un gen puede aumentar el riesgo de padecer determinadas enfermedades.

Chúng ta có hai bản sao của mỗi gen bởi vì chúng ta nhận được một bản sao từ mẹ và một từ cha của chúng ta. Những thay đổi trong hướng dẫn của gen có thể thay đổi cách gen đó thực hiện công việc của nó. Đôi khi những tác động từ những thay đổi đó sẽ nhỏ đến mức bạn sẽ không bao giờ biết được, như làm cho ai đó cao hơn một centimet, và đôi khi nó sẽ là một cái gì đó đáng chú ý nhưng vô hại như là làm cho mắt xanh thay vì nâu. Nhưng sẽ có những lần khác, một sự thay đổi trong gen có thể làm tăng nguy cơ rủi ro cho một số tình trạng ảnh hưởng đến sức khoẻ.

Now that we know that changes in our genes can impact our health, it is important to know how you can find out about these changes. Here is where Genetic Counselors like me can help. Genetic Counselors are healthcare providers who help you understand your genetic health. Genetic counselors can order tests that collect your DNA and send it to a clinical laboratory that looks at your genes to see if there are any changes that may affect how your body is working. These results can tell us important information such as the likelihood for someone to develop a condition such as cancer or the likelihood for someone to have a child with certain birth defects. The result may also provide information about the risk to their children and other family members. When someone already has a medical condition, such as a cancer diagnosis, genetic testing can be helpful as it may influence treatment decisions or prognosis.

Ahora que sabemos que los cambios en nuestros genes pueden afectar a nuestra salud, es importante saber cómo podemos conocer estos cambios. Aquí es donde los asesores genéticos como yo podemos ayudarle. Los asesores genéticos son profesionales sanitarios que le ayudan a comprender su salud genética. Los asesores genéticos pueden solicitar pruebas que recogen su ADN y lo envían a un laboratorio clínico que examina sus genes para ver si hay algún cambio que pueda afectar al funcionamiento de su organismo.

Bây giờ bạn đã biết rằng những thay đổi trong gen của chúng ta có thể ảnh hưởng đến sức khỏe của chúng ta, nên điều quan trọng cần phải biết là làm thế nào để bạn có thể tìm hiểu về những thay đổi này. Đây là lúc mà các chuyên gia tư vấn gen di truyền như tôi có thể giúp bạn. Chuyên gia tư vấn gen di truyền là nhà cung cấp dịch vụ chăm sóc sức khỏe

giúp bạn hiểu về sức khỏe di truyền của bạn. Chuyên gia tư vấn gen di truyền có thể yêu cầu các xét nghiệm thu thập DNA của bạn và gửi nó đến phòng thí nghiệm lâm sàng, nơi sẽ xem xét gen của bạn để xem liệu có bất kỳ sự thay đổi nào trong gen có thể ảnh hưởng đến cách cơ thể bạn đang làm việc không. Những kết quả này có thể cho chúng ta biết những thông tin quan trọng như là khả năng ai đó phát triển một tình trạng như ung thư hoặc khả năng ai đó có con bị những dị tật bẩm sinh nhất định. Kết quả cũng có thể cung cấp thông tin về rủi ro có thể xảy đến cho con cái họ và các thành viên khác trong gia đình. Khi một người đã có một tình trạng y tế, chẳng hạn như chẩn đoán ung thư, xét nghiệm gen di truyền có thể hữu ích vì nó có thể ảnh hưởng đến các quyết định điều trị hoặc dự đoán sự phát triển của bệnh.

Individuals, couples, and families can meet with a genetic counselor at various life stages to talk about their genetic health, these include before getting pregnant, during pregnancy, and when a child or a family member is diagnosed with a significant medical issue such as cancer or autism. They can discuss the chances of someone inheriting a genetic condition, and help families develop a treatment plan when someone does have a genetic condition. However, you do not need to have a family history of a genetic condition to visit a genetic counselor. People who are adopted or who know little about their biological family can also learn about potential health risks for themselves and their future children.

Las personas, las parejas y las familias pueden reunirse con un asesor genético en distintas etapas de la vida para hablar de su salud genética: antes de quedarse embarazada, durante el embarazo y cuando a un hijo o a un familiar se le diagnostica un problema médico importante, como cáncer o autismo. Pueden hablar de las probabilidades de que alguien herede una enfermedad genética y ayudar a las familias a desarrollar un plan de tratamiento cuando alguien tiene una enfermedad genética. Sin embargo, no es necesario tener antecedentes familiares de una enfermedad genética para acudir a un asesor genético. Las personas adoptadas o que saben poco sobre su familia biológica también pueden informarse sobre los posibles riesgos para su salud y la de sus futuros hijos.

Các cá nhân, các cặp vợ chồng và gia đình có thể gặp một chuyên gia tư vấn gen di truyền ở các giai đoạn khác nhau trong cuộc sống để trao đổi về sức khỏe di truyền của họ, bao gồm trước khi mang thai, trong khi mang thai, và khi một đứa trẻ hay một thành viên trong gia đình được chẩn đoán có vấn đề về sức khoẻ quan trọng như ung thư hoặc tự kỷ. Họ có thể thảo luận về khả năng ai đó thừa hưởng một tình trạng di truyền và giúp các gia đình xây dựng kế hoạch điều trị khi ai đó có bệnh di truyền. Tuy nhiên, bạn không cần phải có tiền sử gia đình về bệnh di truyền để đến gặp một chuyên gia tư vấn gen di truyền. Những người được nhận nuôi hoặc ít biết về gia đình ruột thịt của họ cũng có thể tìm hiểu về những rủi ro sức khỏe tiềm ẩn có thể xảy đến cho bản thân và những đứa con tương lai của họ.

Many people choose to see a genetic counselor before or during a pregnancy. A genetic counselor's role in this setting is to provide information and support. They do not

help people choose specific traits for their future children and cannot change a baby's DNA. Genetic Counselors also do not tell someone they should have an abortion or termination if a baby has significant genetic and/or medical issues. Instead, they provide information and support to individuals and couples, allowing them to make informed decisions about their pregnancies based on their values and beliefs.

Muchas personas deciden acudir a un asesor genético antes o durante el embarazo. El papel de un asesor genético en este contexto es proporcionar información y apoyo. No ayudan a las personas a elegir rasgos específicos para sus futuros hijos y no pueden cambiar el ADN de un bebé. Los asesores genéticos tampoco dicen a nadie que debe abortar o interrumpir el embarazo si el bebé tiene problemas genéticos o médicos importantes. En su lugar, proporcionan información y apoyo a individuos y parejas, permitiéndoles tomar decisiones informadas sobre sus embarazos basadas en sus valores y creencias.

Nhiều người chọn gặp chuyên gia tư vấn gen di truyền trước hoặc trong khi mang thai. Một vai trò của chuyên gia tư vấn gen di truyền trong trường hợp này là cung cấp thông tin và hỗ trợ. Chuyên gia không giúp mọi người chọn những đặc điểm cụ thể cho những đứa trẻ tương lai của họ và không thể thay đổi DNA của em bé. Chuyên gia tư vấn gen di truyền cũng không nói với ai đó rằng họ nên phá thai hoặc chấm dứt thai kì nếu em bé có vấn đề di truyền và / hoặc y tế quan trọng. Thay vào đó, chuyên gia cung cấp thông tin và sự hỗ trợ cho các cá nhân và các cặp vợ chồng, cho phép họ đưa ra quyết định sáng suốt về việc mang thai dựa trên giá trị và tín ngưỡng của họ.

These days many people are curious about their genes and their ancestry. There are many at-home ancestry kits that you can buy, and some include information about your health as well. Genetic testing through a genetic counselor is different than these at-home kits. The tests that genetic counselors order use a different technology, are more comprehensive and accurate and are from labs that meet strict standards for quality. Information from the at-home kits is not meant to be used to make medical decisions.

Hoy en día, muchas personas sienten curiosidad por sus genes y su ascendencia. Hay muchos kits de ancestros que se pueden comprar en casa, y algunos incluyen también información sobre la salud. Las pruebas genéticas realizadas por un asesor genético son diferentes de estos kits caseros. Las pruebas que solicitan los asesores genéticos utilizan una tecnología diferente, son más completas y precisas y proceden de laboratorios que cumplen estrictas normas de calidad. La información de los kits caseros no debe utilizarse para tomar decisiones médicas.

Ngày nay, nhiều người tò mò về gen và tổ tiên của họ. Có rất nhiều bộ dụng cụ xét nghiệm gen tại nhà mà bạn có thể mua, và một số cũng bao gồm thông tin về sức khỏe của bạn. Xét nghiệm gen di truyền thông qua một chuyên gia tư vấn gen di truyền khác với những bộ dụng cụ tại nhà. Các xét nghiệm mà các chuyên gia tư vấn di truyền yêu cầu sử dụng một công nghệ khác, toàn diện và chính xác hơn và là từ các phòng thí nghiệm đáp ứng các tiêu chuẩn nghiêm ngặt về chất lượng. Thông tin từ bộ dụng cụ tại nhà không nên được sử dụng để đưa ra các quyết định về sức khoẻ.

When someone chooses to do a test through a genetic counselor that looks at their genes, there are laws in place in the US that keep genetic information private and make sure employers and health insurance companies are not able to fire people or drop their insurance coverage based on the results of a genetic test. Your results and conversations with your genetic counselor are also completely private and cannot be shared by your genetic counselor with anyone outside of your healthcare team.

Cuando una persona decide someterse a una prueba genética a través de un asesor genético, en EE.UU. existen leyes que protegen la privacidad de la información genética y garantizan que los empresarios y las compañías de seguros médicos no puedan despedir a nadie ni cancelar su cobertura basándose en los resultados de una prueba genética. Los resultados y las conversaciones con su asesor genético también son totalmente privados y éste no puede compartirlos con nadie ajeno a su equipo sanitario.

Khi ai đó chọn làm xét nghiệm thông qua một chuyên gia tư vấn di truyền để xem xét gen của họ, luật tại Hoa Kỳ yêu cầu giữ thông tin gen di truyền riêng tư và đảm bảo chủ lao động và các công ty bảo hiểm y tế không thể sa thải người dân hoặc bỏ bảo hiểm của họ dựa trên kết quả xét nghiệm di truyền. Kết quả và cuộc trò chuyện của bạn với chuyên gia tư vấn gen di truyền của bạn cũng hoàn toàn riêng tư và không thể được chia sẻ bởi chuyên gia tư vấn gen di truyền với bất kỳ ai ngoài nhóm chăm sóc sức khỏe của bạn.

Genetic counselors can help you find out how much of the cost of testing will be covered by your insurance before you decide to do anything. They can also help you figure out other forms of payment including finding certain tests that may be free to you. Genetic counselors provide patients with information, support, and guidance for making informed decisions about their genetic well-being. If you are interested in seeing a genetic counselor, you can ask your doctor or visit NSCG.org to find a genetic counselor near you.

Los asesores genéticos pueden ayudarle a averiguar qué parte del coste de las pruebas cubrirá su seguro antes de que decida hacer nada. También pueden ayudarle a averiguar otras formas de pago, incluida la búsqueda de determinadas pruebas que pueden resultarle gratuitas. Los asesores genéticos proporcionan a los pacientes información, apoyo y orientación para tomar decisiones informadas sobre su bienestar genético. Si está interesado en consultar a un asesor genético, puede preguntar a su médico o visitar NSCG.org para encontrar un asesor genético cerca de usted.

Chuyên gia tư vấn gen di truyền có thể giúp bạn tìm hiểu về việc bảo hiểm của bạn sẽ chi trả bao nhiêu tiền cho việc kiểm tra xét nghiệm trước khi bạn quyết định làm bất cứ điều gì. Họ cũng có thể giúp bạn tìm ra các hình thức thanh toán khác bao gồm tìm các xét nghiệm nhất định có thể miễn phí cho bạn. Chuyên gia tư vấn gen di truyền cung cấp cho bệnh nhân thông tin, sự hỗ trợ và hướng dẫn để họ đưa ra quyết định sáng suốt về sức khỏe di truyền của họ. Nếu bạn quan tâm đến việc gặp một chuyên gia tư vấn gen di truyền, bạn có thể hỏi bác sĩ của bạn hoặc ghé thăm NSCG.org để tìm một chuyên gia tư vấn gen di truyền ở gần bạn.

Appendix H: Demographics of Total Responses

Language	**N**	**%**
English	785	93.9%
Spanish	20	2.4%
Vietnamese	31	3.7%
Gender Identity	**N**	**%**
Female	435	52.0%
Gender-Queer	1	0.1%
Male	384	45.9%
Non-Binary	15	1.8%
Transgender	1	0.1%
Age	**N**	**%**
Younger than 30	252	30.1%
30-39	227	27.2%
40-49	174	20.8%
50-59	172	20.6%
60-69	8	1.0%
70 or older	3	0.4%
Race or Ethnicity	**N**	**%**
American Indian or Alaska Native	12	1.4%
Asian	60	7.2%
Black or African American	42	5.0%

Hispanic/ Latino	32	3.8%
More than one	4	0.5%
Native Hawaiian or Pacific Islander	1	0.1%
White	685	81.9%
Birth Place	**N**	**%**
born in the US	775	92.7%
born outside of the US	61	7.3%
Highest Level of Education	**N**	**%**
Elementary (up to grade 8) or less	1	0.1%
High school graduate or GED or less	10	1.2%
Some College or technical school	255	30.5%
College graduate	328	39.2%
Graduate degree	242	28.9%
Annual Household Income	**N**	**%**
$19,999 or less	18	2.2%
$20,000- $49,999	40	4.8%
$50,000 -$99,999	371	44.4%
$100,000-149,999	377	45.1%
$150,000 or more	17	2.0%
I prefer not to answer	13	1.6%
Religious Affiliation	**N**	**%**
Buddhist	42	5.0%
Christian	738	88.0%

Hindu	3	0.4%
Jewish	5	0.6%
Muslim	5	0.6%
More than one affiliation	18	2.2%
no affiliation	25	3.0%
Insurance Coverage	**N**	**%**
No health insurance	16	1.9%
a plan through Indian Health Service	1	0.1%
government-provided insurance plan	44	5.3%
Military related health care	3	0.4%
plan purchased through an employer or union	753	90.3%
private nongovernmental plan	17	2.0%