Latinos and genetics:
Addressing the disparity of Latino research participation in genetics

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Abstract

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Despite the growing presence of Latinos in the United States, research is falling short of proportionally representing Latinos among genetic research studies. Low rates of minorities engaging in biomedical research is an issue that has been addressed through the NIH Revitalization Act of 1993 but the Act has had little effect in addressing the minority representation gap over the past 2 decades. Increasing ethnic diversity in research participation by engaging Latinos in genetics research is challenging. Under current conditions, the responsibility to address this disparity lies with the research community. This content analysis identifies factors related to Latino participation in research identified in a literature review. These factors include issues of distrust, limited understanding of genetics, and research ethics which fail to address Latino cultural nuances. The factors identified are relevant to researchers and provide recommendations for future research, such as the use of acculturation measures and transcreation.

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Introduction

As the fastest-growing minority group in the US, Latinos currently account for 17% of the total population and this proportion is expected to rise to 25% by 2050. In 1994, the NIH established an inclusion mandate requiring representation of minorities and women in NIH-funded research 2014) but this mandate has been unable to address the disproportional representation of minorities, including Latinos. Within the field of biomedical research, disparities in minority representation in genetics research in particular have been especially challenging to address, as 96% of all population based genetics studies are conducted on non-Hispanic whites. (Bustamante, Burchard et al. 2011)

Latinos in the US

Increased minority participation in research is essential for meeting the challenges of major demographic changes in the US. Latinos are already the largest minority group and are expected to be the largest ethnic group in the US, surpassing non-Hispanic Whites, by 2050. It is anticipated that individuals of mixed race, as well as Latinos, Asian Americans, and Pacific Islanders will experience the greatest increases in the immediate future but by 2050, a quarter of the American population will be Hispanic and non-White persons will constitute the majority of the US population by 2042.(Chen, Lara et al. 2014, Dang, Rodriguez et al. 2014)

Despite the evidence that Latinos are emerging at a formidable rate, they face many disadvantages, including disadvantages in healthcare access. In a 2002 National Health Interview Survey, only 53% of Spanish dominant and 75% of bilingual or English dominant speaking Latinos in the US had medical insurance. (Vadaparampil, Wideroff et al. 2006) Of all the major racial and ethnic groups in the US, Latinos use fewer health care services, are less likely to enter the health care system for any type of care, and often work for employers who do not provide health insurance. (Burchard, Borrell et al. 2005) Latinos also currently under-utilize genetic technologies. A national study of persons who had received genetic testing between the years 1998 to 2000 showed that only 7 people out of 646, or 1.08%, were Hispanic. (Vadaparampil, Wideroff et al. 2006) Although not widely used among Latinos, there is evidence that Latinos would benefit from increased used of genetic medicine. Prevalence of genetic disorders and birth defects in Latinos are similar to other population groups, but some evidence suggests higher prevalence at birth of neural tube defects and Down syndrome, and some thalassemias and related hemoglobinopathies are found more frequently in Latinos than in non-Hispanic whites, although less often than in blacks. (Penchaszadeh 2001) Although the need for genetic medicine for Latinos exists, lack of awareness places Latinos at a disadvantage, both in genetics medicine and genetics research.

There is a particular need for genetic medicine for Latinos in cancer genetics. In 2010, a national study of 46,276 patients who received genetic testing for *BRCA 1/2* mutations (genetic predisposition to breast cancer) found only 4% (1,936) of those patients were Hispanic. (Vadaparampil, McIntyre et al. 2010) However, between 2010 and 2030, the projected increase in cancer incidence rate is 99% for minorities, compared with 45% for the population at large. (Chen, Lara et al. 2014) Latinos have the highest rate of stomach, liver, uterus, cervix and gallbladder cancer mortality, although the most common cancers, such as breast and colon, are found to be at lower or equal rates to non-Hispanic whites. Breast cancer is the most common cancer among Latinas and a higher proportion are diagnosed at a late-stage compared to non-Latina Whites. Despite recent data suggesting increased risk for *BRCA* mutations in Hispanics, cancer genetics services for hereditary cancers are underutilized in this population.(Quinn, McIntyre et al. 2011)

Representation in research

The biomedical research culture has been fraught with injustices toward ethnic minorities, whether intentional or not, and continues to see the impact of this history in participation rates. (Shavers, Lynch et al. 2002) Research study populations simply do not reflect the diversity of the population of the diseases or conditions of interest, and despite a growing trend toward addressing this, research is still falling short. Readily available and current resources to determine the rates of minority groups in biomedical research are difficult to come by, as much of the data available is specific to certain research fields. Nonetheless, conclusions can be drawn from the evidence available. For example, fewer than 2% of National Cancer Institute-sponsored clinical trials focus on any racial/ethnic minority population, meaning that the overwhelming majority of cancer studies focus on cancer type and not on proportionate representation of disease burden. (Chen, Lara et al. 2014) Similarly, participation in HIV research studies is overwhelmingly from white males despite the fact that Hispanic and black men have higher rates of HIV infection. (Shavers, Lynch et al. 2002) And despite a growing concern about mental health, Latinos have been a largely untapped demographic in mental health studies. (Rodriguez 2012)

This underrepresentation in research is especially troubling as Hispanic populations in the US are an ideal population with which to conduct population genetics research: Hispanic families tend to have more individuals than other ethnic groups, are mostly descended from a small number of founders that can be traced back to a short number of generations ago and are characterized by a great deal of environmental and phenotypic homogeneity. (Rodriguez 2012) Additionally, because so many Hispanics are recent immigrants, ecological studies can be conducted to determine if specific health conditions are environmentally or genetically influenced by looking at the rates of disease from migrant and home populations in successive generations. (Burchard, Borrell et al. 2005) And lastly, evidence from current and past research in Latino populations has demonstrated novel findings, such as novel *BRCA* variants and founder mutations from Hispanic women. (Vadaparampil, McIntyre et al. 2010)

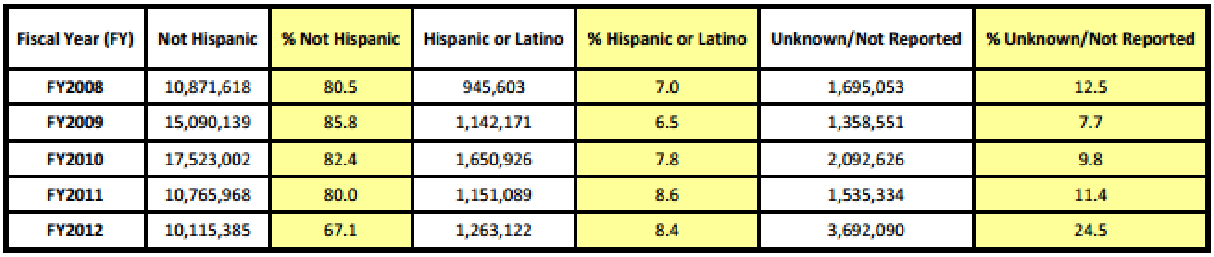
NIH Revitalization Act

Due to the increasingly commercial and global nature of biomedical research in the past 3 decades, minority participation has been increasing. (Joseph and Dohan 2009) Still, a disparity in research involving minorities exists and measures to address it continue under a federal policy mandate which went into effect over two decades ago. As part of the 1993 Revitalization Act, the National Institutes of Health (NIH) established guidelines on the inclusion of women and minorities and their subpopulations in NIH funded research involving human subjects, including clinical trials. Exclusion of minorities or women may be considered only when there is a "clear and compelling rationale and justification established to the satisfaction of the relevant [Director] that inclusion is inappropriate with respect to the health of the subjects or the purpose of the research." (NIH 2000) The mandate states that cost for including minorities in research is not an acceptable reason for exclusion, but limited representation due to geographical location may be considered by NIH staff reviewers. A statement in the guidelines claims that the NIH evaluates the research portfolio to "address areas with knowledge gaps or which need special attention to advance the science involved," and may "consider funding projects to achieve a research portfolio reflecting diverse study populations." (NIH 2000) An update in 2001 included a statement on reporting gender and racial analyses for phase III clinical trials, mostly to update the minority categorization based on the 1997 census categories, but does not address participant reporting on other types of biomedical research. (NIH 2001)

NIH-funded studies must provide an inclusion criteria statement on grant applications and will provide researchers with support to assure that statement will be acceptable. (NIH 2000) In 2012, the most recent publication year, fewer than 3% of all applications submitted had an unacceptable inclusion criteria statement. (Chen, Lara et al. 2014) Reporting of participation by minorities and women has existed since the mandate was implemented in 1994 and the NIH annual reports on inclusion include aggregate data on gender and racial representation. This has led to an increase in reporting of minority participation in NIH funded studies, from 1.5% in

1997 to 57% in 2011. (Chen, Lara, & Dang, 2014) While the numbers on both reporting and minority participation have been on an upward trend in the past 20 years, the percentage of Hispanic or Latino participants in clinical research is, nevertheless, still much lower than the representative proportion of the total US population. Table 1 shows the rates of Hispanic, non-Hispanic and unknown/unreported ethnicity participant enrollment in NIH-funded clinical studies between fiscal years 2008-2012. According to the US Census, as of 2013, 17% of the US population identifies as Hispanic or Latino, while 62% identify as White alone, not-Hispanic. (US Census Bureau 2014)

Table 1- Total enrollment for domestic NIH Clinical Research Ethnic Categories from FY 2008-FY 2012



Fiscal Year (FY)	Not Hispanic	% Not Hispanic	Hispanic or Latino	% Hispanic or Latino	Unknown/Not Reported	% Unknown/Not Reported
FY2008	10,871,618	80.5	945,603	7.0	1,695,053	12.5
FY2009	15,090,139	85.8	1,142,171	6.5	1,358,551	7.7
FY2010	17,523,002	82.4	1,650,926	7.8	2,092,626	9.8
FY2011	10,765,968	80.0	1,151,089	8.6	1,535,334	11.4
FY2012	10,115,385	67.1	1,263,122	8.4	3,692,090	24.5

(NIH 2013)

While the inclusion criteria have demonstrated an earnest attempt to increase minority representation, the NIH can do little else to increase minority representation with current resources. While increased attention to the matter is a step towards meeting the disparity, the NIH does not have the authority, nor should it, to enforce a minority quota in the research projects they fund.   Minority representation in clinical research is still falling short of proportional to the US population despite the mandate, indicating that the issue is much larger than reporting and researcher inclusion statements. Ultimately the inclusion criteria policy has only partially addressed a substantial gap in minority participation rates. However, bringing attention to sampling bias through a mandate in the research development phase can have downstream effects on research and translational outcomes.

> *Since a primary aim of research is to provide scientific evidence leading to a change in health policy or a standard of care, it is imperative to determine whether the intervention or therapy being studied affects women or men or members of minority groups and their subpopulations differently. To this end, the guidelines published here are intended to ensure that all future NIH-supported biomedical and behavioral research involving human subjects will be carried out in a manner sufficient to elicit information about individuals of both genders and the diverse racial and ethnic groups and, in the case of clinical trials, to examine differential effects on such groups. Increased attention, therefore, must be given to gender, race, and ethnicity in earlier stages of research… (NIH 2001)*

Regardless of the shortcomings of this mandate in achieving more a representative research population, creating a standard ethnicity/race reporting guideline and tracking rates of minority participation are indeed a success of the NIH mandate. After all, it is through such data that we can describe exactly how trends in the rate of minority participation have been affected by preceding policies.

Given the limitations of the NIH's reach, what now is evident is that the responsibility of a more representative research population is a burden that the research community must bear. Raising awareness and compelling researchers to actively engage with minority populations is a challenge, but an important one towards addressing the gap. The disproportionate representation in research leads to disproportionate benefits of scientific discovery in healthcare and policy, research which is, after all, publically funded by all Americans, regardless of ethnicity. But the implications of this disparity are much larger than simply an argument towards social justice for minorities. Scientific rigor is at stake, especially when considering the investigation of genetic components of health.

Genetic Sampling Bias

Sampling bias in population sampling of NIH-funded genetics research is pronounced, as 96% of participants in genome wide association studies (GWAS) published before 2009 were non-Hispanic whites. (Bustamante, Burchard et al. 2011) The benefits to increasing the ethnic pool of research participants will yield benefits for all and increasing generalizable knowledge in genomic research is necessary to reducing the harms of biased ascertainment of data.

Genetic cancer risk assessment research is primarily conducted on non-Hispanic white samples and the harm of sampling bias can be demonstrated currently in the example of breast cancer genetic susceptibility, although is also relevant to several other types of cancer. While genetic susceptibility to breast cancer is identified in various other ethnic groups, most ethnic minority studies of the nature and prevalence of *BRCA* mutations focus on African Americans. (Lagos, Perez et al. 2008) This is the case despite a 2007 population-based study from a cancer registry which reported that Hispanic breast cancer patients had higher *BRCA1* mutation prevalence when compared to non-Ashkenazi Jewish whites, African Americans and Asian Americans, as well as suggesting a *BRCA* founder mutation specific to Mexican-American populations in the US. (Quinn, McIntyre et al. 2011) Cancer clinical trials, which permitted the majority of advancements in cancer treatment, may fail to address unique genetic and environmental factors of specific populations, such as Latinos, that may place them at disadvantages for diagnosis and treatment in the future. (Chen, Lara et al. 2014)

Decreasing sampling bias in research through increasing minority participation and increasing diversity in genetics research will also lead to scientific and statistical advantages. A broader range of data will lead to a more comprehensive view of genetic susceptibility of diseases, allow comparison of disease-related genetic variants across a spectrum of populations, and permit more accurate measures of susceptibility prevalence and relative risk. (James, Yu et al. 2008) Without representation from diverse communities, research cannot ensure the generalization and external validity of results. In terms of cancer research, comparing genetic variants across populations, measuring susceptibility and determining cancer risk are based solely on the denominator and if the denominator is not of a representative population, the actual risk, and likely the genetics-based prognosis, is weakly supported.

Addressing the issue of sampling bias due to low diversity of participants may seem challenging, but data from clinical trial participation suggests that increasing minority representation can be accomplished. The proportion of minority adults enrolled in cancer clinical trials is not representative of the proportion of minority adults in the US with cancer, although this is not the case in pediatric cancer studies, where the opposite is seen. In pediatric studies, the proportion of minorities to the US population is equal or greater to their respective minority group and is believed to be due to increased willingness due to perceived benefits, such as better medical treatment, of research participation. (Chen, Lara et al. 2014) Additionally, a range of data suggests that minority participants are equally or more willing to participate in biomedical research than whites. (Sanderson, Diefenbach et al. 2013, Chen, Lara et al. 2014) If a more representative proportion of minority groups are participating in biomedical research and are willing to participate, achieving this with Latinos in genetics research is feasible.

Some research has been conducted on Latino participation in genetics research such as in cancer genetics, prenatal screening and biobanking, but because data on this topic are still relatively sparse, using research from clinical and healthcare applications of genetic testing and medicine in this population can begin to address the knowledge gaps with regard to genetics research participation. What can be concluded from the research conducted thus far is that it is challenging to engage minorities in genetics research, but Latinos present an especially complex challenge.

Objectives

This analysis intends to inform researchers about the factors affecting research participation in order to draw attention to the underrepresentation of Latinos in genetics research. The primary aim is to identify the unique barriers Latino populations face when participating in genetics research. A broad perspective of the current knowledge of minority participation in biomedical research and Latinos in biomedical research was necessary to describe the unique factors in a sub-population and a specialty field of research, namely Latinos and genetics research.

The secondary aim was to identify facilitators for engaging Latinos in genetics research in order to provide some recommendations for addressing current barriers. Some articles addressed both barriers and facilitators, but most did not, so it was also important to find articles that discuss facilitators to research participation. This included articles that discussed research design considerations, such as communication facilitators, for both Latino participants and genetics research.

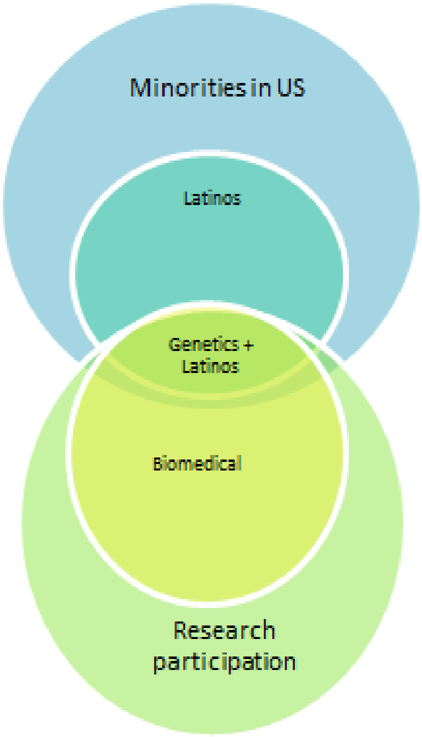
These aims were addressed through a literature review of articles discussing public perceptions and attitudes about genetics research as well as that of researchers in study design considerations. The intention was to bring awareness of the issues in order to encourage researchers to justly address the unique needs of Latinos in research participation.

Methods

This analysis is based on a literature review which evaluated three topics: Minority participation in biomedical research, Latino participation in biomedical research, and Latino participation in genetics research. These three topics, or tiers, were selected to find the factors that serve as barriers and facilitators to research participation by these populations. An additional search, minorities and genetics, provided background to better address the research aims. Common factors were found across the three tiers, but organized based on the frequency and volume of content throughout the literature. While this literature review was not exhaustive, these articles highlighted common factors found throughout the many published journal articles discussing these topics.

This Venn diagram (Diagram 1) demonstrates how I conceptualized the multiple layers in my investigation. This three-tiered analysis attempts to tease apart some of the factors within each category and while many factors overlap, this analysis found several predominant themes surfacing in each tier. A factor was deemed dominant due to the high frequency and volume of discussion in the literature. A major challenge in developing the analysis was the dearth of research articles available on genetics and Latinos. The three-tiered approach strengthened the argument by identifying factors which are described in other settings and other populations.

Diagram 1- Conceptual Model



The literature review began with a search of journal articles. Searches were conducted using Web of Science Core Collections (http://webofknowledge.com.offcampus.lib.washington.edu) or PubMed (http://www.ncbi.nlm.nih.gov) and only included articles in English. Keywords were provided by the author or by the search engine as Keywords Plus. Articles published from 1990 through 2014 from American institutions only were included. Searches were conducted as described below using Boolean search methods and article abstracts reviewed to determine if the study described used qualitative methods such as interviews and focus groups or used mixed or quantitative methods such as structured surveys and descriptive data. Only articles providing empirical data of relevance to the research aims were included.

Throughout this analysis, I drew examples from clinical genetics applications and applied these as evidence towards an argument in addressing research participation. Due to the lack of available sources, particularly those from genetics research and Latino participation, some concepts from clinical genetics were adapted to research considerations and, where they do, I state how they apply. Additionally, some information about measures which have successfully addressed clinical disparities are discussed in order to inform researchers about resources available to encourage engagement with this population.

The first tier search on minorities and biomedical research began with a literature search on Web of Science using the search terms “minority clinical trials research participation biomedical research recruitment disparities” and which resulted in the identification of twelve citations. Articles which only addressed one minority group or a specific condition or disease were excluded. After reviewing the abstracts, four articles were selected based on the breadth of topics they covered. Although few papers were selected, they adequately discussed a diverse set of factors influencing participation in order to support this argument. (Table 2)

Table 2- Tier 1 selected literature

Title	Keywords
Racial Differences in Factors that Influence the Willingness to Participate in Medical Research Studies (Shavers, Lynch et al. 2002)	African American, Blacks, Minorities, Medical Research, Participation, Tuskegee Study, Research Barriers.
Are Racial and Ethnic Minorities Less Willing to Participate in Health Research? (Wendler, Kington et al. 2006)	Minorities, health research
Twenty Years Post-NIH Revitalization Act: Enhancing Minority Participation in Clinical Trials (EMPaCT): Laying the Groundwork for Improving Minority Clinical Trial Accrual Renewing the Case for Enhancing Minority Participation in Cancer Clinical Trials (Chen, Lara et al. 2014)	cancer clinical trials, National Institutes of Health Revitalization Act, minorities, clinical trial, disparities.
Diversity of Participants in Clinical Trials in an Academic Medical Center: The Role of the 'Good Study Patient?' (Joseph and Dohan 2009)	clinical trials, recruitment, accrual, cancer, provider roles.

As a subset of this tier, a second search for genetics and minorities, was conducting using Web of Science using the search terms "minority genetics research participation" and resulted in the identification of twenty-seven citations. Articles that did not discuss participant or researcher perspectives, only addressed one minority group or a specific condition or disease were excluded. This resulted in eight articles which were selected based on the breadth of themes discussed. (Table 3)

Table 3- Tier 1 second search, selected literature

Title	Keywords
Willingness to participate in genomics research and desire for personal results among underrepresented minority patients: a structured interview study (Sanderson, Diefenbach et al. 2013)	Genomics research, interest, interviews, Patients, personal results
Perceived disadvantages and concerns about abuses of genetic testing for cancer risk: differences across African American, Latina and Caucasian women (Thompson, Valdimarsdottir et al. 2003)	Genetic testing, cancer risk, attitudes, ethnic differences; Medical mistrust
"What are they going to do with the information?": Latino/Latina and African American Perspectives on the Human Genome Project (Schulz, Caldwell et al. 2003)	Racial disparities; Hispanic perspectives on genetics; African American perspectives on genetics; perspectives on genetics
Community perceptions of genomic research: Implications for addressing health disparities (Isler, Sutton et al. 2013)	African Americans, Hispanic Americans, genetic research, health knowledge attitudes, practice, health disparities
Genomics for the world (Bustamante, Burchard et al. 2011)	Ancestry, minorities, genomics
Engaging diverse populations about biospecimen donation for cancer research (Dang, Rodriguez et al. 2014)	Biobanking, biospecimens, Asian Americans, African Americans, Hispanics, medically underserved
Strategies and Stakeholders: Minority Recruitment in Cancer Genetics Research (James, Yu et al. 2008)	Cancer Genetics Network, minority recruitment, cancer
Warranted Concerns, warranted outlooks: a focus group study of public understanding of genetic research (Bates, Lynch et al. 2005)	Genetic technology, public opinion, warrants, public understanding of science, USA

A second tier search, on Latinos and biomedical research, began with a search on Web of Science using search terms "Hispanic Latino research methods research recruitment" and resulted in sixteen results. Articles not relevant to biomedical research were excluded. After a review of the abstracts, three articles were selected based on their breadth of themes discussed. (Table 4)

Table 4- Tier 2 selected literature

Title	Keywords
Issues in Biomedical Research: What Do Hispanics Think? (Ulrich, Thompson et al. 2013)	biomedical research, Hispanic, research ethics, recruitment
Development of a linguistically and culturally appropriate booklet for Latino cancer survivors: Lessons learned (Solomon, Eberl-Lefko et al. 2005)	Translation, transcreation, culturally appropriate, Latino, cancer education, Spanish
Methodological concerns for non-Hispanic investigators conducting research with Hispanic Americans (Lange 2002)	Research methods, Hispanic, Latinos

A third tier search, on Latinos and genetics, began with a literature search on Web of Science using search terms "Hispanic Latino recruitment participation genetics" and resulted in 10 citations identified. Due to the low number of results, an additional search on PubMed using the same search terms was conducted and resulted in 26 citations, with a total of 32 unique articles identified from both searches. Articles which did not address recruitment methods or issues in recruitment, research on a specific gene and not generalizable to other genetics studies, or that didn't collect data on participant or researcher perspectives were excluded. Two articles from both searches were selected (Table 5).

Table 5- tier 3 selected literature

Title	Keywords
Challenges in recruiting Mexican women for cancer genetics research (Quinn, McIntyre et al. 2011)	Hispanic, recruitment, genetics, behavioral research
Latino Populations: A Unique Opportunity for the Study of Race, Genetics, and Social Environment in Epidemiological Research (Burchard, Borrell et al. 2005)	Asthma, epidemiology, Hispanic Americans, genetics, Latin America

Because so few articles were found, an additional search of "Latino genetic counseling" was conducted in Web of Science and resulted in the identification of five citations, of which one as selected. After reviewing the fifteen articles that were cited in *Genetic Counseling Issues in Latinos* in Web of Science, four more articles were also selected (Table 6). Articles that did not address recruitment methods or issues in recruitment, research on a specific gene and not generalizable to other genetics studies, or that didn't collect data on participant or researcher perspectives were excluded.

Table 6- Tier 3 second search, selected literature

Title	Keywords
Genetic counseling issues in Latinos (Penchaszadeh 2001)	Latinos, genetics, genetic counseling
Impact of Acculturation (Vadaparampil, Wideroff et al. 2006)	Health survey, genetic testing, Hispanics, acculturation, cancer risk, health disparity awareness
The ethics of a genetic screening study for antisocial personality disorder with Mesoamericans(Rodriguez 2012)	Genetic screening, antisocial personality disorder, ethical issues.
Awareness, perceptions, and provider recommendation related to genetic testing for hereditary breast cancer risk among at-risk Hispanic women: similarities and variations by sub-ethnicity (Vadaparampil, McIntyre et al. 2010)	Hispanic, BRCA, Sub-ethnicity, genetic testing, hereditary breast ovarian cancer, genetic counseling

Many factors were co-occurring in two or three of the tiers, such as cultural nuances and language issues, but were categorized based on the frequency and volume of discussion in the articles. Throughout the analysis there was some overlap between factors in the different tiers, which further underlined the complexity of this problem. Recommendations were provided based on the results of the literature review and may not address all the themes identified, although some recommendations, such as the use of Community Based Participatory Research, can be applied to various factors.

Results

This analysis intends to provide insight for researchers about issues surrounding recruitment and retention of Latinos in genetics research. This topic is of interest to many, but little research has been done to understand the barriers, facilitators and unique considerations of conducting genetics research in this population. The three-tiered analysis allowed a wider scope in terms of literature and themes, and so this analysis begins with a wider question, that of all minorities in any biomedical research.

The first tier provides the background to the research questions by introducing issues in biomedical research participation that affect all minorities, including Latinos, such as distrust. The issue of distrust is found across all three tiers, but discussed here due to the significant impact of historical injustices to ethnic minority groups in research. Distrust is a strong issue in each tier and is possibly also influencing every factor identified in this analysis. It is likely to be the biggest barrier to overcome for engaging Latinos in genetics research participation. A brief discussion on issues for minorities in genetics research identifies factors, such as fear of discrimination, which are not dominant factors for Latinos in genetics research but worth discussing in the context of this argument.

The second tier focuses on issues that Latinos specifically face in biomedical research and touches upon the socio-cultural layers unique to this population. The most notable factor in this tier is due the large proportion of Spanish and Spanish-English bilingual speakers in this group. Language and acculturation factors has brought attention to researchers in addressing culturally and linguistically appropriate materials and resources in research recruitment and retention. This issue carries into the third tier, Latinos and genetics research, which is heavily impacted by low knowledge, awareness and understanding of genetic technologies in addition to language barriers. This factor is especially dominant in this tier because this issue is present for research participation in genetics but also in use and access of genetic medicine.

The factors are sorted into the three tiers and are not exclusive to any one tier.

Major factors identified in the literature

Minorities and biomedical research

- Distrust
- Dissemination
- Willingness and interest
- Perceived benefits

Latinos and biomedical research

- Acculturation
- Study design
- Language
- Prioritization of responsibilities

Latinos and genetics research

- Low knowledge, understanding, awareness
- Cultural nuances
- Latino sub-populations

Minorities in biomedical research

The first tier of the analysis begins by describing the current state of research participation of minorities, as a whole, in biomedical research. The topic of addressing the underrepresentation of minorities in research has been of increasing interest in the past 3 decades. Distrust is a key barrier to minority engagement with research. In addition to distrust, dissemination, willingness and interest and perceptions of benefits are also factors influencing minority research engagement.

Distrust

Distrust is a commonly discussed, if not the most prevalent, theme when discussing minorities' participation in health care and research. Distrust is due to many factors such as historical abuses like the Tuskegee Syphilis case, which are still influential in minority participation rates in biomedical research participation. One study has gone so far as to claim the Tuskegee syphilis study as "the singular reason behind African American distrust of institutions of medicine and public health."(Wendler, Kington et al. 2006) Although policies and protections have been implemented to prevent future misconduct, distrust in medical and governmental authorities is still a major issue among all ethnic minority groups, especially African Americans. Fearfulness of research agendas exists for minorities across the economic spectrum, as those with higher incomes have been reported to cite privacy and confidentiality concerns and fear of needing to pay for research treatments. (Ulrich, Thompson et al. 2013)

Distrust can lead to miscommunication and exacerbate fears about research participation. For example, a multi-site biobanking study emphasizing minority biospecimen donation found that rumors surrounding the study affected participation rates: Vietnamese participants were concerned they would be injected with something harmful when donating blood for the study and Chinese participants in Tampa believed the samples were being sent to Canada where laws on cloning are less strict. (Dang, Rodriguez et al. 2014) In addition to fears about research and researchers, vulnerable populations are often concerned that racial biases from within the medical community may further harm a population's reputation. For example, some African Americans have cited concerns of linking genetic diseases to African origin, such as the erroneous association of the HIV/AIDS origin in Africa and the backlash many African Americans felt from widespread misunderstanding of the significance of this scientific observation. (Bates, Lynch et al. 2005)

Dissemination

Another major theme identified from the literature describing factors affecting minority participation in research was the theme of dissemination. The use of scientific jargon can be intimidating for most people, but when distrust exists between parties, communicating technical terms and complex research methodologies can be especially challenging. One example of this issue arose from a study discussing biospecimen donations for biobanking purposes and found that the word "biobank" has cultural and historical implications that affected participation. (Dang, Rodriguez et al. 2014) For example, when the term "biospecimen" was understood to mean blood, it provoked antagonistic reactions, but once other forms of biospecimens, like saliva and skin, were suggested, reactions to donation were more positive. Terms like biobanking can also be misunderstood and also have negative connotations akin to human cloning and eugenics, so addressing these concerns to create terms based on culturally appropriate vocabulary is vital. Some examples used instead of biobanking were "biolibrary," and "biodatabase," suggesting the term "bank" had an especially negative connotation, perhaps due insinuation of financial banks and further intensified by distrust and fear of the hidden research agenda. (Dang, Rodriguez et al. 2014)

Even after familiarity with biospecimen donation in the form of blood drives, the concept of donating towards cancer research purposes instead of clinical or diagnostic uses is unfamiliar and novel. (Dang, Rodriguez et al. 2014) While technical jargon serves as a dissuading factor, providing participants with more information may not always be effective in recruitment. It is not the amount of information provided that leads to better understanding, it's how the information is presented that matters. (Bates, Lynch et al. 2005) The level of health literacy of the population of interest is a vital consideration in developing materials and methods to assure understanding.

Willingness and interest

While there are different rates of participation for different types of research studies among diverse groups, minorities are generally willing to participate at comparable rates to non-Hispanic Whites. (Chen, Lara et al. 2014) These findings are important because it suggests the research community should work to increase access to health research, rather than investing resources towards changing minority attitudes toward research. (Wendler, Kington et al. 2006) The attitudes which enable the distrust of biomedical research can be addressed by modifications to the research process that increase access to research through applications of methods which are respectful, transparent and considerate of the study population. The recommendations from this analysis present methods identified in the literature to address issues with access to research, such as quality of translations and identifying the needs of a study population.

Perceived benefits

Studies also indicate that minorities are more likely to participate if they believe the research is personally relevant, addresses a condition affecting a friend or family member, and have friends and family who encourage their involvement. (Vadaparampil, Wideroff et al. 2006, Dang, Rodriguez et al. 2014) Compensation for study participation can also be influential. In one study, the majority of minority participants did not expect incentive but reported that monetary incentives would influence their decision to participate. (Dang, Rodriguez et al. 2014)

Providing personal results and offering health services in exchange for participation are also observed to be a benefit for minority participants, although as is discussed later, may be a more complicated matter when discussing genetics. Many studies have suggested that minorities are less likely to participate if they believe they are unlikely to benefit from the research being conducted, especially those minority groups with high rates of medically uninsured.

Genetics and minorities

It was clear in this analysis that distrust of biomedical research permeates into several other factors when persons of an ethnic or racial minority consider genetics research. Perceptions of risk, confidentiality, discrimination and fear of genetics research are notable among minority groups, but is further propagated when there is little knowledge, understanding and awareness of genetics and basic science. (Schulz, Caldwell et al. 2003, Vadaparampil, McIntyre et al. 2010)

Genetics is a difficult concept to grasp for everyone but low knowledge, understanding and awareness of genetics is especially found in minorities. (Bates, Lynch et al. 2005) People of various ethnic backgrounds seem to universally discuss genetics and health outcomes as inheritance and ethnic and racial diversity. Conceptualizing race in terms of differences in physical appearance is viewed as evidence of genetically-based variations among races. While this can be perceived a barrier, knowing the language and concepts laypeople use to discuss genetics can facilitate research participation. The need to discuss genetics in terms that laypeople understand are important to create and interest and increase genetics literacy.

Major findings from the literature review also indicate that minorities fear genetic discrimination, but African Americans are more likely than any other group to fear racial discrimination from genetic technologies. (Bates, Lynch et al. 2005) Non-White minorities groups have also expressed fears of promoting negative eugenics or ideologies of a “superior race,” while non-Hispanic White express fears about confidentiality and privacy. And many minority groups discuss fear of legal consequences of genetic profiling, most notably, fears about forensic genetics in criminal investigations that may lead to imprisonment and deportation. (Isler, Sutton et al. 2013) Lastly, the medically underserved have little faith in the promises of genetic technology and biomedical advances, as some minority groups are still under- or un-insured. (James, Yu et al. 2008)

Latinos in Biomedical Research

As described above, we know that many minorities are willing to participate in biomedical research. (Sanderson, Diefenbach et al. 2013) We also know that many Latinos are curious and interested in research participation. (Ulrich, Thompson et al. 2013) However, after adjusting for age, sex, education, income and location of assessment, Hispanics are more fearful and skeptical of the intentions of biomedical research than non-Hispanic whites. (Ulrich, Thompson et al. 2013) The issue of distrust carries over from a minority participation issue and is further exacerbated by other factors unique to Latinos, particularly language, acculturation and prioritization of responsibilities. In this second tier, we discuss how these factors aggregate and create additional barriers in Latino research participation.

Acculturation

Acculturation is a social process in which people who move into a culturally unfamiliar area begin to adopt characteristics of the foreign culture. Acculturation factors include primary language and length of residence, among others, and may include changes in psychological functioning, language use, cognitive style, personality, identity, attitudes, and stress.(Solomon, Eberl-Lefko et al. 2005) Some associations between various levels of acculturated populations and specific issues in research recruitment and retention are discussed in the literature. Poorly acculturated populations tend to have lower access to health information and lower awareness of medical technology, such as genetics, while highly acculturated populations tend to have greater concerns over confidentiality and higher awareness. (Vadaparampil, Wideroff et al. 2006) Since Latinos in the US have sub-populations with varied levels of acculturation, this can present a challenge when attempting to engage with Latinos in research because issues in research engagement vary across an acculturation scale. Tools to measure acculturation in a population exist, but can prove to be controversial because the accuracy of the findings may not justly address the needs of your population of interest. (Cruz, Marshall et al. 2008) In terms of recruitment and retention, acculturation can be used to identify a population and how to best delegate resources towards addressing the needs of groups within an acculturation scale.

Research considerations

The standard design of biomedical research may alienate specific populations through lack of flexibility in certain study design elements, such as the role of ethnic identity in inclusion and exclusion criteria, and has been a barrier especially when working with Latinos. One example in the literature comes from a study of Hispanic women who have been offered cancer genetics screening from increased breast cancer risk, the study design sorted women by national origin, such as Mexican, Cuban, etc. A woman who identified as Salvadorian and Mexican was not eligible to participate because she didn't fit into the ethnic categories the study developed.(Quinn, McIntyre et al. 2011)

In a sister study to the above mentioned cancer genetics study, a qualitative study attempted to recruit women from Cuban, Mexican and Puerto Rican origin with a personal and family history of breast or ovarian cancer. For some reason, several Mexican women became ineligible to participate in the study because they were unable to name the site of cancer their mother or sister had, a requisite for eligibility. Although they knew enough to know their relative had a "female" cancer, 16 out of the 26 Mexican women screened were unable to describe the specific cancer type. Non-disclosure of cancer diagnosis to family members is one example of how Latino cultural nuances impact several aspects of research engagement and will be discussed further in depth. While this may not seem as an excessively stringent exclusion criteria, having knowledge about barriers like these prior to designing your study can influence the criteria used in order to increase access to research participation.

Other barriers to participation identified in this analysis include access to transportation for research activities, perceived costs of participation and lack of flexibility in scheduling, and although these are not unique to Latinos, they are described are larger barriers when compared to other ethnic minority groups. (Chen, Lara et al. 2014) What the above examples really highlight is how considerations for the population of interest must be taken in account when designing a research study. Allowing participants to have a choice in how they self-identify is one example of how research consideration can meet the needs of this population.

Language

Translation of research materials between languages can be a complex and involved process, sometimes more so than the average biomedical researcher is capable or willing to manage. Translation requires specialized language skills, reiterative processes and dedicated resources, tasks which may not align well with the biomedical research funding objectives. But in order to do research justly for Latino populations, careful consideration of Spanish-language research materials is important towards demonstrating respect.

Knowledge of the target population in a study is also important because the heterogeneity of Latinos can present challenges in translation of study materials. Spanish is the most commonly spoken language among Latinos but regional dialects vary and must be considered in the translation process. (Lange 2002) Additionally, many pre-Colombian indigenous languages are actively used in Latin America and while most countries are predominantly Spanish speaking, levels of Spanish literacy vary regionally.

Addressing cultural elements in the translation process, such as *colectivismo,* using social networks like family and friends and *familialismo,* family over individuals, are vital to accurately conveying messages across languages and cultures. Materials need to include graphics and visual elements that are appealing for Latino audiences, as it demonstrates a desire to relate and understand their background.

Prioritization of responsibilities

Some studies have found that Latinas have lower income and lower rates of medical insurance than other minority women groups. (Vadaparampil, McIntyre et al. 2010) The behavior of seeking resources to improve their current economic status is placed highly as a priority for Latinos, so participation in biomedical research ranks as very low as a priority and may very well account for some of the reasons why Latinos participate at lower rates than other ethnic groups. Additionally, Latinos may view emerging technologies as inaccessible and therefore have lower interest in participating. (Thompson, Valdimarsdottir et al. 2003)

Latinos in Genetic Research

The third and final tier of this analysis compounds the aforementioned issues in research participation in minorities and Latino participation in biomedical research, but offers examples of how Latinos are especially vulnerable to low knowledge, cultural, and sub-population issues that impact genetics research participation. Some is known about how these directly impact research participation but more is known about how Latinos perceive genetics through clinical genetics applications. I argue that the gap in knowledge can be filled by these examples because the factors identified are not exclusive to clinical genetics and so are applicable to research applications.

Low knowledge, understanding, awareness of genetics

The effect of low knowledge, understanding and awareness of minorities of biomedical research is a problem which may be especially important for Latinos. A study of 4,313 Hispanic and 18,316 non-Hispanic White participants in the 2000 National Health Interview Survey found that Hispanics had the lowest awareness (20%) of hereditary cancer testing, whereas non-Hispanic White showed the highest awareness. (Vadaparampil, Wideroff et al. 2006) Several examples from the clinical genetics setting explain how low knowledge, understanding and awareness can impact genetics research participation.

The use of biomedical jargon that is not translated appropriately in colloquial terms has led to confusing situations, and while the following examples highlight how misunderstandings impact clinical care, it can be easily translated into research applications. In one example of Latino women in a reproductive health setting, pregnant women were offered a test for Alpha-fetoproteins (AFP). Even after explanation that AFP is not influenced by dietary protein, some women insist the cause is dietary and did not take the abnormal result seriously. (Browner, Preloran et al. 2003) The word “protein” is often used by researchers when explaining research objectives to participants in genetics research and may even be used in the informed consent process. Using specialized jargon may cause confusion, as demonstrated in the above example, and can impact the quality of consent in genetics studies.

While jargon can lead to misunderstanding, cultural nuances can also lead to poor understandings of risk. For example, the non-directive nature of genetic counseling may be too casual for cultures that embrace *autoritarismo*, a health belief that authority figures such as doctors and health care professionals make the orders in a medical setting. Some Latinos believe that if the provider doesn't order or prescribe a treatment, the condition is not very serious. (Browner, Preloran et al. 2003) Perceptions of genetic risk as ineffectual in a clinical setting may be perceived as ineffective medicine, and may therefore be a deterrent for participating and sustaining participation in genetics research.

In addition to other concerns about research participation, low knowledge permeates health literacy and impacts the quality of consent, understanding of research materials, and can impact the quality of data collection. It also highlights how subtle some of these misunderstandings can be when discussing genetics and how low knowledge and understanding of genetics feeds into behaviors and beliefs about health. As will be discussed in the conclusion, addressing low knowledge in genetics will be important towards increasing research participation for Latinos in genetics research.

Ethics of research and cultural factors

Undermining Latino cultural values in genetics research presents a further unique challenge in research ethics. While the Belmont Report delineates ethical guidelines for studies with human subjects, values such as *familialismo*, and *autoritarianismo* do not necessarily align well in biomedical research ethics. (Ulrich, Thompson et al. 2013) *Familismo* suggests that family values supersede those of the individual, and therefore suggest group harms are considered more carefully among Latinos. Genetics research poses potential group harms that are unique to this field of research, and the risk involved in participation is a threat to this value.

Autoritarianismo is a value in which a family member has authority over the family and will make the decisions for the best interest of the family. This can be particularly complicated for genetics research as distrust and low knowledge, understanding and awareness is found among members of the family. Traditional gender roles in Latino culture may cause conflict when participating in genetics research, as Latinas have been found to have higher levels of shame from a positive cancer genetic test result. (Thompson, Valdimarsdottir et al. 2003) This shame may also feed into the observed non-disclosure cases in research recruitment.

The issue of non-disclosure among Latinos has been noted throughout the literature, particularly in cancer diagnosis. Some evidence suggests Latinos may be more unwilling to share a cancer diagnosis with family members or may be inclined to withhold details about their condition and for hereditary cancers, this can be especially detrimental. In addition to poor communication of cancer diagnosis, the large numbers of recent immigrants and the separation of families across continents can make communication about a health diagnoses more difficult, thus exacerbating low knowledge that affects research participation. (Quinn, McIntyre et al. 2011)

Little is known about how Latinos perceive risks and benefits of genetics research. Some of the immediate benefits of research participation are viewed favorably, particularly return of results and compensation for participation. (Dang, Rodriguez et al. 2014) And while these personal benefits are valued, benefits of participation that may extend to relatives and descendants are also highly prized for Latinos. *Familialismo*, the belief that the family unit is of utmost importance in all matters, is a well-documented social behavior known to impact the health of Latinos, particularly in health care access. Although stated to be important to various minority groups, the perceptions of benefits in participating in studies of conditions in which there are affected family member or friends are strong motivators for Latinos. (Sanderson, Diefenbach et al. 2013) *Familialismo* helps explain why perceived benefits in genetics research are especially important for Latinos but can also help explain why participating in genetics studies is perceived to be riskier for Latinos. Some evidence suggests that Latinos perceive more risk and disadvantages to genetic testing than African Americans and whites. (Lagos, Perez et al. 2008)

The cultural nuances described for Latinos are not intended to enforce stereotypes, but rather, to highlight what the literature has identified to be unique issues for engagement in biomedical research. But as the final section of this tier describes, attempting to make generalizations about Latinos in the US is not always advisable.

Population Heterogeneity

Latinos are a particularly interesting population to study because of the presence of both highly preserved indigenous groups and unique mixtures of indigenous, African and European heritage. Although Latino refers to persons of Latin American descent and Hispanic refers to persons of Spanish ancestry, a single label fails to account for the diverse languages, politics, geography and culture which shape the socioeconomic factors influencing health. In one such case, economics influenced opinions. One study demonstrated that Latinas perceived more disadvantages, compared to African American and Caucasian women, to genetic testing for cancer risk, but when controlling for socio-demographic variables, no difference was found between Latinas and other ethnic groups. (Thompson, Valdimarsdottir et al. 2003) Although Latinos are often perceived to be disadvantaged, it is important to be aware of the range of Latinos across different variables, such as education, language and economic status.

Throughout the discussion of results, the common thread is consideration of the needs of the population of interest. By presenting these results in tiers, researcher can become aware of specific factors and their relationship to one another and become aware of some approaches for addressing these issues in their own work. When discussing cultural nuances, it’s difficult to separate this from language and low knowledge factors, and so measures that address several of these factors would be beneficial and efficient in a research project. As discussed in the recommendations, researchers can be empowered by this knowledge and apply some methods to address these known issues.

Recommendations

Despite the complexities described in this analysis, the issues surrounding Latino participation in genetics research can and should be managed. Many of the articles analyzed presented some insight into recommendations for addressing many barriers for Latino research participation. It should be noted that these recommendations suggest additional resources be used to address the unique issues Latinos in genetics research face, particularly if the research project hasn't taken these into considerations in the planning stages or if staff are unfamiliar with these issues. Despite the stage in research, these can still be considered to enhance recruitment and data collection and aid in retention and dissemination. Although these recommendations place the responsibility for engaging with Latinos in genetics research on the researchers, this issue is not otherwise being addressed in any meaningful, organized fashion. These recommendations are intended to provide support to researchers who believe that the collective efforts of the research community may lead to a major paradigm shift that will address this issue from a systemic vantage point.

The four recommendations address methods that are explicitly stated in the literature, but also encompass several of the factors identified. All of the factors identified can be addressed in one of more of these recommendations and subsequently, all of these recommendations address one or more factors.

Developing trust

If trust is the dominant barrier to minority participation in biomedical research, addressing the issue of trust is vital to improving current trends. Strong relationships developed within communities, the individuals therein and research institutions offer a way to engage in research through a trusted broker. Community research models have emerged as one method to increase minority participation and retention in research by a collaborative process from start to finish. One commonly used model is Community Based Participatory Research (CBPR), which can be tailored to fit the different needs of specific populations and research designs. Based on principles of community engagement, co-learning and equitable power and control of studies and resources, CBPR can address disparities in topics related to the inclusion of diverse populations in various types of research. (Dang, Rodriguez et al. 2014)

Other research designs in which a trusted broker is involved can be used to address the issue of trust. Using existing partnerships between academic or government institutions with community centers, houses of worship and advocacy groups to promote research can successfully engage with Latino communities that may be otherwise marginalized from research engagement. Recruitment and research activities at these centers provides legitimacy and assurance, which increases trust and willingness to participate. Cooperation with the community groups can provide a cultural broker who can address the language and cultural nuances of the population. It can also increase access to research and diminish barriers with prioritization of responsibility for Latinos in research participation.

Reaching out to community groups will enhance many aspects of research with Latinos and genetics, but it does require time and energy to accomplish. This recommendation can be challenging but the advantages are many, such as creating a long-term partnership for many other studies in the future, a dedicated research population and specialized staff and resources to work with Latinos.

Acculturation

Acculturation factors are often used when researching Latino populations because evidence suggests that acculturation levels can be used as a socioeconomic variable. Acculturation measures can be used to guide research agendas by providing some insight into specific issues, such as access to healthcare, language and cultural factors, which will likely need to be addressed in a research study with this population. (Vadaparampil, Wideroff et al. 2006) Due to the varied sub-groups within Latino populations, acculturation measures can also help to stratify and identify sub-groups to refine a population for a specific research topic. Capturing group level effects can lead to identifying populations of interest to conduct specific research studies. Recent research findings in Mexican-American women, for example, led to the discovery of novel *BRCA* mutations and interest in identifying this sub-population for research can be difficult if the larger population is diverse. Using an acculturation measure as a proxy can help to identify and refine the study population and enhance data collection for follow-up research. (Cruz, Marshall et al. 2008)

Using acculturation scales in research can help to direct where resources should be dedicated. Poorly acculturated Latino populations have greater concerns about time commitment and low awareness, whereas highly acculturated Latino populations have concerns about confidentiality and genetic discrimination in a work setting. (Vadaparampil, Wideroff et al. 2006) Highly acculturated Latinos tend to speak English more dominantly than Spanish, but share many of the same cultural nuances, such as fatalism, with poorly acculturated Latinos who predominantly speak Spanish. (Lagos, Perez et al. 2008) Knowledge of acculturation measures can inform the expected translation resources needed, population targeted materials and provide foresight into challenges that could arise during research activities.

Jargon

Genetic literacy and education is low overall for all persons, regardless of sociocultural background. Attention must be given to the ways in which genetics information is presented to the lay public. Evidence suggests that using the terms and concepts that laypeople use and relate to is more effective than offering a didactic approach. (Bates, Lynch et al. 2005) As cited in the examples from clinical genetics, the use of technical words may confuse and intimidate Latinos and efforts to communicate these concepts across both language and cultural barriers are necessary. Dedicating resources to understanding how to best communicate complex genetics language to a participant audience is vital to creating more accessible research engagement.

Discussing genetics in terms of inheritance and differences between racial and ethnic groups are universally accepted and understood by Latinos. Using this knowledge can create interest with Latinos about genetics research, but careful and considerate dialogue is necessary by a person who can facilitate a conversation that is culturally sensitive but also well versed in genetics concepts. Research materials should also consider the use of more accessible language and use diagrams and visual aides to enhance understanding. This is especially important in the informed consent process, where technical language is necessary but must be conveyed to assure understanding.

Language

"Transcreation" is a process where English-language material is translated into Spanish and adapted to feel more natural for native speakers and can be an ideal alternative to basic translation. (Lange 2002) As mentioned earlier, Latinos are not a culturally or linguistically homogenous population, so transcreation may require the use of bilingual and bicultural translators from different national origins. The use of specific terms may vary across the differing national origins, and if attempting to create widely understood media, it is important to avoid regionalism and colloquialisms. (Solomon, Eberl-Lefko et al. 2005) Most researchers agree that in order to conduct research justly, it is important to also consider non-language elements of translation. For example, some research has demonstrated that traditional data instruments, such as the Likert scale or ranking order scales, may not be well understood by some Latinos and may lead to poor quality data. The issues with the Likert scale are not a language issue, but rather a conceptual one and transcreation can address some of these issues in order to achieve conceptual congruence or equivalence. (Lange 2002, Solomon, Eberl-Lefko et al. 2005)

Conclusion

The intention of the three-tiered analysis presented here was to view the issue of Latino research participation in genetics by taking a wide view and focusing in to identify what unique barriers exists at each level. Focusing on each level to identify factors within tiers was done with the intention of finding the exclusive factors in each tier, but instead led to discovering that most factors are not unique to any one tier. Much like social determinants of health, the factors influencing research participation are varied, interwoven and enabled by historical and institutional barriers. The parallels between barriers to healthcare and barriers to research participation are documented, but nonetheless, I was surprised to discover how applicable these were in my own analysis. A familiarity with social determinants of health enabled my analysis to draw from examples of clinical genetics to meet the deficiency of research in the topic of Latinos and genetics research.

The deficit of genetic literacy among minorities was discussed briefly, but it is important to note that genetic literacy is low for most populations in the United States. To make claims that genetic literacy is low among Latinos, a claim which I have some evidence to support, is saying that it is below an already low average across all groups, and therefore can provide little information about how it impacts Latinos differently. However, given the additional disadvantages Latinos face, it is one component among many worth mentioning that compromises rates of research participation.

Latinos are currently deemed a disadvantaged minority group in the United States, a status that is likely to improve over time. Like most immigrant populations have demonstrated throughout our history, they will overcome many barriers to success, include healthcare access. However, until more attention is brought to adequate representation in all aspects of health and medicine, Latinos will continue to face unique challenges in genetics research and outcomes of research. Increasing research participation can directly impact the quality of research being conducted but continued engagement as only a participant will limit the direction of genetics research and where research dollars will be invested. Distrust will continue to dissuade research engagement by Latinos, Latino cultural nuances may be ignored in research applications, language considerations may ignored in research materials, all of these issues may persist until more participants can relate to researchers and researchers to their participants.

Although measures can be taken to increase participation of Latinos in genetics research, conducting the research does not promise that the benefits and risk of research outcomes will be equitable. Inclusion, in and of itself, does not ensure equity. While researchers may make earnest efforts towards inclusion and increasing diversity, it is important to note the disproportionate distribution of the benefits of research still present major barriers to increasing participation of minorities in research.

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