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Learning from Latino Voices: Focus Groups' Insights on Participation in Genetic Research

Priscilla Martinez, Mphil, PhD,

Associate Scientist, Alcohol Research Group/Public Health Institute, 6001 Shellmound Ave, Suite 450, Emeryville, CA 94568, T: 510-898-8560

Cory Cummings, PhD(c),

Doctoral Candidate, School of Social Work, Virginia Commonwealth University, Richmond, VA

Katherine J. Karriker-Jaffe, PhD, and

Scientist, Alcohol Research Group/Public Health Institute

Karen G. Chartier, PhD

Assistant Professor, School of Social Work, Virginia Commonwealth University, Richmond, VA

Abstract

Background and Objectives—There is a paucity of genetics research examining alcohol use among Latinos. The purpose of this study is to examine Latino perceptions of participation in alcohol studies that collect biological samples, an important precursor to increasing their participation in genetics research.

Methods—A synthesis of the literature addressing participation of racial/ethnic minorities in alcohol genetics research was undertaken. We developed a framework of themes related to barriers and facilitators for participation, which we then used to analyze two focus groups held with 18 Latino participants.

Results—From the literature review, we identified nine themes related to facilitators of and barriers to participation. They are, on continua: curiosity to disinterest; trust to mistrust; understanding to confusion; safety to danger; inclusion to exclusion; sense of connection to disconnection; hope to despair; ease to hassle; and benefit to cost. Another theme emerged from the focus groups: previous experience to no previous experience with health research.

Conclusions—Applying the themes from the literature review to Latino perspectives on providing biological samples for alcohol research helps expand their definition and applicability. Consideration of these themes when designing recruitment/retention materials and strategies may encourage Latino participation in alcohol genetics research.

Scientific Significance—An understanding of these themes and their significance for Latinos is offered in the form of “guiding questions” for researchers to consider as we strive for more inclusive research. Focus group participants were Mexican American; future research should

Correspondence to: Priscilla Martinez.

DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this paper.

further explore perspectives of this heterogeneous demographic group by studying other Latino subgroups.

Keywords

Latino; Hispanic; biological samples; research participation; barriers; facilitators

BACKGROUND

Latinos/Hispanics (hereafter, Latinos) are the largest and fastest-growing racial/ethnic minority group in the US, yet are grossly under-represented in genetics research on alcohol use [1]. This underrepresentation is of particular concern given evidence showing that Latinos are 1) at a greater risk of alcohol-related health problems at the same level of consumption as their White counterparts [2], an example being their elevated risk for alcohol-related liver disease [3], and 2) are more likely to experience recurrent or persistent alcohol dependence [4]. One presumed reason Latinos have not been the focus of many alcohol genetics studies is because of the admixture of their genetic background, which represents Native American, European, and African heritages [5]. However, González Burchard et. al. have noted this complexity presents an opportunity to better understand the influence of genetic, social, and environmental factors on differences in health outcomes [6]. When alcohol genetics research equitably represents Latinos, the advancements produced by such research, including advancements toward precision medicine, will be more applicable to Latinos.

Participation in alcohol genetics research necessarily requires the collection of biological samples with which to obtain genomic information and conduct subsequent analyses. There is a relatively small but expanding body of literature addressing the participation of racial/ethnic minorities in any type of health research collecting biological samples; however, Latino representation remains limited. One such study conducted among Latinos suggest their under-representation in research requiring biological samples may be because Latinos prioritize family obligations over personal choices when making decisions to participate in research requiring blood tests such as genetic testing [7]. In this study, family loyalty [vs. personal health care needs] was seen as integral to Latino culture, particularly for women adopting traditional female roles. Another reason may be the challenges to subject recruitment because of a mistrust of biomedical research and stigma associated with such research [8]. There may also be institutional-level barriers or fewer opportunities to participate in research if subject recruitment is not conducted by institutions that serve Latino communities [9].

There is thus a need to understand the barriers and facilitators that Latinos perceive about participation in alcohol genetics research and to create more responsive recruitment and follow-up efforts based on this knowledge [10–13]. Moreover, given the paucity of data on the recruitment and participation of Latinos in alcohol research collecting biological samples, an understanding of the extant literature on racial/ethnic minority participation in genetics research would help to provide a knowledge base to inform further research specific to Latinos in this area. Identifying recruitment and follow-up strategies to address these

issues may help reduce barriers to participation in alcohol genetics research and improve rates of providing the necessary biological samples. Such methods are imperative for ensuring Latinos are effectively included in the methodological advances of alcohol genetics research.

OBJECTIVES

The present study aimed 1) to synthesize the extant literature to develop general themes related to barriers and facilitators to participation of racially/ethnically diverse groups in genetics research, and 2) to examine in depth Latinos' thoughts and attitudes about participating in alcohol research collecting biological samples using data from focus groups with Latino participants to build upon the themes from the synthesized literature.

METHODS

Aim I

To address the first aim, we conducted a systematic review of literature regarding recruitment of racially/ethnically diverse groups (especially African Americans and Latinos) for the purposes of genetic research. Due to the scarcity of literature specific to alcohol genetic research, we broadened the search to encompass studies of genetic testing for alcoholism and any type of genetic research conducted with racially/ethnically diverse groups. Key words including genetic* research, ethnic, improv* recruitment, African American, Hispanic, Latino, minority, and alcohol were queried using Google Scholar, a comprehensive web search engine for scholarly literature including journal articles, holdings of university repositories and other sources. Much of the limited published literature in this area focuses specifically on African Americans, or at the very least includes specific content targeted to this group. In addition to the initial literature that was located, studies with high relevance to this topic were used to identify similar studies through the use of the 'related to' query search function. In total, 57 studies were identified.

Analysis—After identification, the studies were coded and thematically analyzed in an effort to reduce the data into condensed and meaningful categories related to facilitators and perceived barriers of racially/ethnically diverse groups about participation in genetic research studies. Preliminary coding categories were derived from 10 high-relevance studies (with high relevance defined as studies that addressed alcohol genetic research and/or provided explicit attention to perceptions of racially/ethnically diverse groups as a substantive focus of the article) [11, 12, 14–21]. The remaining studies were unitized, or divided into meaningful data segments, coded using preliminary code categories, and thematically analyzed. Themes were extracted based on the coded content to reflect a more detailed and meaningful understanding of each of these categories.

Aim II

To address the second aim, we conducted 2 gender-specific focus groups to assess the thoughts and attitudes of Latinos about providing biological samples in alcohol studies. Focus groups were gender-specific to facilitate a comfortable atmosphere within which to

hold the discussion given that men and women are known to have different drinking patterns [22], which could impact views on participation in alcohol research collecting biological samples. Participants were identified and recruited via our partner organization, Cultiva la Salud, located in Fresno, CA. Cultiva la Salud is a program of the Public Health Institute (PHI) that aims to engage and inform residents of the San Joaquin Valley to advance personal, family, and community health. Participants were recruited via an email sent to members and affiliates of Cultiva la Salud explaining the focus groups' purpose and eligibility. Recipients of the email were eligible if they were self-identified Latinos, aged 18 and older, who reported having had 2 or more drinks on any single day in their lifetime. We applied this alcohol use criterion because we aimed to recruit people with lifetime exposure to alcohol, recognizing that genetic liability [23] and physiological consequences of use [24] cannot be assessed in those abstain from drinking. These criterion also addressed the knowledge that Latinas tend to have lower rates of alcohol use than Latino men [22].

Before the focus groups began, participants provided informed consent and completed a short paper survey. We recruited 10 participants for the women's focus group, and 8 for the men's focus group. All of the participants identified as Mexican-American, and all but 2 were born in the US. Participant ages ranged from 25 to 77. All participants reported drinking at least one alcoholic beverage in the last 12 months. One-third of the sample completed high school as their highest level of education, and another third had completed some college. All but two participants identified their religious affiliation as either Catholic or Christian.

To facilitate the focus groups, the 2 group facilitators used a semi-structured written guide that was approved by the Institutional Review Board at PHI. The topics covered were 1) previous experiences with and ideas about the benefits of and barriers to providing a biological sample for use in alcohol research; 2) opinions about providing different kinds of biological samples collected at home and sent in by mail, including blood and saliva, and about different kinds of tests for research, such as physiological (cortisol levels [25] or liver enzymes [26]) and genetic tests; 3) the meaning of participation in such research; and 4) what messaging and information might be provided by researchers to improve participation and encourage the provision of biological samples. This last topic was addressed by having participants respond to a recorded telephone recruitment message and a printed postcard reminder to provide a biological sample. We did not assess participants' thoughts about participation in alcohol genetics research per se; however, participants were queried about their thoughts about having biological samples collected for DNA. Focus groups were conducted in English and averaged 90 minutes. We followed standard procedures for conducting focus group sessions [27, 28].

Analysis—Qualitative content analysis was used to analyze the data from these focus groups. After each focus group, the facilitators documented and discussed initial general impressions about its process and content. Next, the facilitators listened to the audiotaped discussion and took general notes to familiarize themselves with content of the transcripts. Subsequently, focus group audio recordings were transcribed, reviewed, and compared by both facilitators. Both facilitators independently coded transcripts using an a priori coding scheme based on the categories identified in Aim I. After coding a segment of the first

transcript, facilitators compared and discussed codes to arrive at a shared conceptualization of category meaning. Lists of data units contained in each category for both facilitators were compared, reconciled, and used to extract sub-themes relevant to each of these categories. An additional category also was identified during the coding process.

RESULTS

Aim I – Themes from the Literature

We identified nine general themes from the literature related to facilitators and barriers for researchers to consider when engaging racially/ethnically diverse groups in alcohol genetics research. These were conceptualized along the following continua: curiosity to disinterest; trust to mistrust; understanding to confusion; safety to danger; inclusion to exclusion; sense of connection to disconnection; hope to despair; ease to hassle; and benefit to cost. The nine themes are described in Table 1.

Aim II – Focus Group Themes

The themes identified in Aim I were then applied to the Latino focus group data gathered in support of Aim II, in order to provide insights into Latino perceptions on research participation involving biological samples, with special attention to content related to the collection of DNA. In addition to the 9 themes identified in the literature review, another theme emerged from the focus groups that can be conceptualized along the continuum of previous experience to no previous experience with research. For example, one female participant said “I did one study, about 9 years ago, when my daughter was diagnosed with Leukemia. They took blood, saliva, and urine, I want to say. And the reason why I did it, is I want to be able to help, so they can find what is causing that.” Table 2 provides a summary statement for each of the themes based on the data shared by focus group participants. In addition, sub-themes relevant to each topic are presented.

The gender-specific nature of the focus groups allowed for further consideration of gender differences, which are presented here. The most commonly occurring theme was trust-mistrust in the women’s group and connection-disconnection in the men’s group as they relate to the process and products of research. The women expressed considerable concern about the information that could be obtained from DNA and the potential consequences of providing such information to researchers. Such consequences included the loss of privacy and negative financial consequences if made available to third parties, such as health insurance companies. The women also expressed concern about the implications of genetic information for their own health and their families’ health, as well as concerns about the reliability and meaning of this information and its links to health outcomes. One woman said “I would just be concerned because things are so unreliable with DNA. Like you could say you are more likely predisposed to this based on your DNA, but that’s not a guarantee.” The men also expressed concern about genetic information and its consequences, but focused more on feeling a sense of connection to and having a clear understanding of the purpose and outcomes of the research they were participating in. One man said “It’s just not knowing, not knowing what is going on behind the curtain that is hard. That is what people are wondering. ’Cause I mean honestly, you can give your DNA to someone if you know

what it's about." In summary, concerns voiced by women tended to be related to uncertainty about the meaning of genetic information and worries over personal and/or familial safety, while men tended to focus on informational and motivational needs. Implications of these perspectives and themes for improving the participation of Latinos in alcohol research collecting biological samples are discussed below.

DISCUSSION

The themes identified in the literature review were useful in conceptualizing the thoughts and ideas Latinos expressed about participating in alcohol research collecting biological samples. Applying these themes to Latino perspectives helps expand the meaning and definition of these themes, and their applicability to increasing Latino participation in genetics research on alcohol use. The themes that we identified in the broader literature review were all reflected in the focus group data, again with the addition of a newly emergent theme surrounding previous experience, which emerged from the focus groups.

It is noteworthy that we did not identify any new themes regarding participation in alcohol research collecting biological samples in the Latino focus groups compared to the literature review, with the exception of having previous experience with health research or providing biological samples or not. That the other themes were applicable to and identifiable in the Latino focus groups may speak to the similarity of concerns about participating in alcohol research collecting biological samples across many racial/ethnic groups. In regards to the emergence of the theme related to previous exposure, we attribute the discussion around this topic to having explicitly asked the participants about previous experiences with providing biological samples and participating in health research, which sparked conversations around this idea. Many of our participants voiced little or no direct exposure to research, and much of their discussion describing research and its capabilities was often informed by references to popular culture and fictionalized media. In addition to being about willingness to participate, this lack of exposure could also be viewed as a barrier at the institutional level, such that alcohol research collecting biological samples is not being conducted at the institutions or in the communities Latinos utilize or inhabit [9]. Indeed, many participants noted a greater willingness to participate in alcohol research collecting biological samples if they were approached in familiar spaces, such as their doctor's office or the local farmer's market. This would suggest it is important to consider the location and research partners of an alcohol genetics study in order to maximize opportunities for Latinos to participate. The studies we reviewed supported this notion of limited encounters with genetic research and genetic testing within racially/ethnically diverse communities, and affirm the need for educational outreach efforts aimed at increasing awareness and visibility of this type of research [7, 10, 18].

Overall, similar to African Americans and other racial/ethnic minorities, our Latino participants expressed salient concerns about trusting and feeling connected to the purpose, methods, and implications of alcohol research collecting biological samples. For instance, Scott and colleagues [12] found that African American interest in genetic testing for alcohol dependence was most often motivated by personal concerns over threat of the disease and a desire to provide information to children, and apprehensions related to participation were

often related to concerns over the accuracy of testing and results. Our participants voiced similar motivations related to a desire to gain personally relevant health information, both for themselves and for their children; but also expressed reservations regarding the trustworthiness of genetic findings and analytic techniques. Perhaps more unique to our sample, participants shared how compelling they felt that genetics research on alcohol was because of the significance of alcohol problems in their local communities. While we did not assess personal or familial experiences with alcohol problems and/or treatment as part of the self-administered survey or focus group discussion, many participants mentioned someone in their family and/or community who has struggled with alcohol problems. One male participant said, “Alcoholism runs in my family. It goes back generations”, and another noted, “We all know alcohol really effects our communities really, really badly.” People who have experienced alcohol problems themselves or in their families may be particularly open to participating in alcohol genetics research since the topic may be especially salient to them. Exploring Latinos’ ideas about different areas of alcohol genetics research (e.g., familial aggregation because of genetic or environmental similarities, genetic ancestry, and genetic liability for how much people drink, or alcohol-related liver disease) is a worthwhile aspect to consider in future research, as thoughts and attitudes may differ by topic, and study materials and recruitment strategies can be adapted accordingly.

Specific to alcohol genetics research, participants expressed serious misgivings about providing DNA samples, citing worries about the implications of disclosing such personal information for research purposes. For example, participants expressed concerns about the impact of the discovery of an illness on their health insurance, and what it would mean for them to know if they had a predisposition to an alcohol use disorder. Participants also made references to previous research misconduct (e.g., Henrietta Lacks, The Tuskegee Syphilis Study) as reasons to mistrust researchers collecting biological samples, conducting genetic studies, and studying racial/ethnic minorities. These concerns help explain why Latinos may be less willing to participate in alcohol studies collecting biological samples, and in alcohol genetics research in particular. It may improve recruitment among Latinos if alcohol genetics researchers address these concerns directly to reduce the reasonable reluctance to participate in alcohol genetics studies. Similarly, concerns voiced by our female participants regarding uncertainty of genetic information and over personal and/or familial safety, and by our male participants regarding informational and motivational interests, could also be addressed directly to improve participation. One way this could be achieved is through careful consideration of all text and images used in recruitment and follow-up materials. Similar concerns have been well documented amongst other racial/ethnic groups regarding the potential for misuse, discrimination, and other potential negative ramifications for sharing genetic information [15, 17, 18, 21]. Nonetheless, our participants also noted the importance of Latino participation in alcohol genetics research and provided strategies to make participation more accessible and comfortable for Latinos, such as face-to-face recruitment and accessible, comprehensive study information. As potential next steps, we present questions below for researchers to consider when developing study materials that may improve their functionality in communicating with Latino audiences.

Latinos in the US are a diverse group of people from many countries with varying citizenship, residency, and degree of genetic admixture. Our participants were Mexican-

American men and women who were primarily US-born and living in the Fresno, CA area. This limits the generalizability of our findings to similar Latino subgroups and geographic locations. Nevertheless, the information we learned from this study could help researchers to design and develop recruitment and retention efforts for more inclusive studies that can capitalize on the richness in genetic ancestry of Latinos. *Below we suggest a number of guiding questions for researchers to consider, the responses to which should be tailored to the specific population under study.*

1. How well do researchers establish and maintain a sense of trust, safety and respect for participants? What does this trust look like?

Themes addressed: Trust to Mistrust; Safety to Danger

Considerations: Consider the significance that participants place on sharing biological samples and that this request may be perceived as very personal in nature. Strategies to build trust might include incorporating resources that are already seen as trusted in recruitment efforts, paying special attention to recruitment materials to convey a sense of legitimacy and authenticity, and diligently working to anticipate and respond to concerns about research aims, procedures, and findings.

2. How are researchers connecting their agendas with the perspectives of participants, particularly Latino participants and their values, priorities (such as their children and health issues), and knowledge?

Themes addressed: Connection to Disconnection; Understanding to Confusion; Benefit to Cost

Considerations: Establishing a connection can be challenging, but this can be aided by establishing the significance of your research for racially/ethnically diverse groups early in the recruitment process; know your audience and what is important to them. Also, demonstrating an ongoing commitment to work supporting the well-being of racially/ethnically diverse communities is vital.

3. How does the research convey a message that change is possible, attainable, and sustainable? What is being done to instill a sense of hope that resonates with Latino communities that prevention/treatment/intervention is possible and will be accessible for them and their loved ones?

Themes addressed: Hope to Despair

Considerations: As researchers, it is our duty to be good stewards and ambassadors for science. To accomplish this, we need to consider how our research agendas target and support the needs, concerns, and strengths of communities that have been historically disenfranchised and consequently distanced or alienated by scientific advancement; furthermore, we need to communicate this intention in genuine and explicit ways.

4. How effectively do recruitment efforts appeal to participants' sense of curiosity about research and engage them in a dialogue about why research is important?

For instance, how does research relate to entrenched, intergenerational, culturally significant issues, such as the pronounced effects of alcohol on the Latino family? How are perceived costs to the Latino community anticipated and mitigated by researchers, and how are benefits understood and maximized?

Themes addressed: Curiosity to Disinterest; Benefit to Cost

Considerations: Recruitment efforts are an opportunity to engage the interest and curiosity of participants around what research is and what it is capable of. Many people have limited exposure to research opportunities and scientific advancements outside of fictionalized or sensationalized popular media. Despite this, participants are often inquisitive and sincerely interested in the work we are doing and what we are learning from it; we need to capitalize on this interest.

5. How are racial/ethnic minorities incorporated in, represented by, and benefiting from this research? What is being done to make participation accessible, attainable, and hassle-free for all members of these diverse communities?

Themes addressed: Inclusion to Exclusion; Ease to Hassle

Considerations: Research is an opportunity for reciprocity. Participants are sharing valuable knowledge/data/biological samples with us, and in turn, we need to consider what knowledge/resources/insights we can share with them. Inclusion of racially/ethnically diverse groups in research extends beyond a more representative sample and requires researchers to thoughtfully consider how all aspects of research design might foster or prohibit greater inclusivity and equity in representation.

Considering the themes and related questions we identified here when designing recruitment and retention methods may help improve the quality and applicability of future research. Beyond genetics research aiming to improve the inclusion of racial/ethnic minorities, any research working to understand the relationship between alcohol use and biological factors that necessarily collects biological samples would benefit from equitable representation of diverse racial/ethnic groups.

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Table 1

Thematic analysis of the literature: Facilitators and barriers for engaging racially/ethnically diverse groups in genetic research

Themes	Description
1. Curiosity to Disinterest	The intensity of the intellectual draw that research participation holds for participants.
2. Trust to Mistrust	The level of trust, respect, and rapport experienced by participants, particularly as a means of overcoming historical and present-day concerns regarding research and the medical establishment.
3. Understanding to Confusion	Participants' level of comprehension across a variety of topics related to the research.
4. Safety to Danger	The sense of security participants experience regarding research participation
5. Inclusion to Exclusion	The perceptions of how respective groups have been treated in relationship to research, both a specific research project and the broader institution of research.
6. Connection to Disconnection	The ideological relationship between the perspective of the researcher and/or the research agenda with the participant.
7. Hope to Despair	A participant's orientation that change is or isn't possible and that they (as an individual) can help advance science to prevent alcohol problems impacting their communities.
8. Ease to Hassl	The facility with which participation occurs.
9. Benefit to Cost	The significance attributed to various pragmatic factors as participants engage in decision-making regarding research participation.

Table 2

Application of themes to Latino focus group content: Themes informed by Latino voices

Theme	Relevant Content from Latino Focus Groups
Curiosity to Disinterest	<p><u>Summary:</u> Participants voiced interest in various aspects of the research agenda, shared important insights into what may pique (or dissuade) curiosity in a study.</p> <hr/> <p>Participants find interest in:</p> <ul style="list-style-type: none"> ○ The overall purpose of the research project. ○ Results of what scientists and society are learning and how it is helping. <p>Interest can be influenced by:</p> <ul style="list-style-type: none"> ○ <i>Presentation.</i> Research materials need to be visually appealing. Audio and live voices in recruitment need to be enthusiastic and engaging. ○ <i>Key phrases.</i> Key words can pique interest, such as “health-related”, “children”, “family”, or “Latino community”.
Trust to Mistrust	<p><u>Summary:</u> Building trust was critical; participants alluded to a pervasive culture of mistrust, fueled by scams, paranoia, and “sketchiness” of requests for personal information.</p> <hr/> <p>Concerns about research that affect trust:</p> <ul style="list-style-type: none"> ○ What is going to be done with research findings and biological samples. ○ How reliable is genetic science and what are researcher’s intentions in general. <p><u>Significance of DNA:</u> There was considerable worry about giving DNA to anyone and what the potential ramifications could be. “DNA is your whole identity”; “...don’t clone anybody”.</p> <p>Sources of information contribute to level of trust:</p> <ul style="list-style-type: none"> ○ Trusted: doctors, health fairs, and official companies. ○ Variations: participants suggested trust can vary: “NIH means nothing to my Tía María”, while others were reassured by affiliation with a study funded by the NIH (National Institutes of Health). <p>Presentation influencing trust: the look and style of communications: logos, good cardstock, signatures, quality pictures, personable and engaging voices enhance trust; other aspects could trigger mistrust: poor quality materials, “gimmicky” phrases, sounding “desperate” for participants.</p>
Understanding to Confusion	<p><u>Summary:</u> Participation in research studies was the result of a deliberative process and informed by what information is offered and how it is conveyed.</p> <hr/> <p>Research-related informational needs:</p> <ul style="list-style-type: none"> ○ Who is doing the research, how it is funded, biological sample handling, study progress, what new knowledge is being learned and how will it be used, how alcohol affects the health of the participant, their family, and community. <p>How information is delivered:</p> <ul style="list-style-type: none"> ○ Content: be approachable (not too technical or wordy) ○ Source: should come from a trusted source; Sci-Fi movies, murder mystery novels, and TV shows were named as the primary sources of information regarding genetic research, resulting in many concerns about how research “might” be used.
Safety to Danger	<p><u>Summary:</u> Participants assess the general safety of participation based on a number of considerations, such as the threat posed by study procedures and an overarching concern for sharing personal and especially genetic information.</p> <hr/> <p>Procedures:</p>

Theme	<p>Relevant Content from Latino Focus Groups</p> <ul style="list-style-type: none"> ○ Unannounced phone calls: “we don’t even know who the person is on the other end of that call.” <p>Privacy:</p> <ul style="list-style-type: none"> ○ Health information being disclosed beyond study – “Will the postman see I participate?”, “Can an insurance company find out I have a condition?”, “What if my DNA gets left somewhere or doesn’t make it to the lab?” <p>Sharing genetic data:</p> <ul style="list-style-type: none"> ○ Providing DNA seen as huge amounts of sensitive information - You have “my whole identity”, “You know everything about me”. ○ Concerns that testing could identify compromising health information.
Inclusion to Exclusion	<p><u>Summary:</u> <i>Including Latinos in research studies was seen as a draw for participation. However, misgivings were also voiced regarding why minorities were being recruited.</i></p> <hr/> <p>Importance of Latino inclusion in research:</p> <ul style="list-style-type: none"> ○ “It did pique my interest when he said that a lot of the research that is going on right now is on the Whites. So that was kind of like, oh, there is research happening already, but there are no Latino representatives.” <p>Concerns about recruiting minorities:</p> <ul style="list-style-type: none"> ○ Apprehension about focus on race/ethnicity and what implications could mean for Latino community fueled by historical injustices (Tuskegee, Henrietta Lacks). <p>Strategies to promote inclusion:</p> <ul style="list-style-type: none"> ○ Get to know us: “Important that researchers get to know us and our community.” ○ Find a gatekeeper: People and trusted businesses in the community can act as research champions.
Connection to Disconnection	<p><u>Summary:</u> <i>Participants emphasized a number of points to consider in facilitating a sense of connection to a research project during recruitment.</i></p> <hr/> <p>Points to consider when establishing connection:</p> <ul style="list-style-type: none"> ○ Consider places (doctor’s office, health fairs, churches, farmer’s markets) and people (family member or friend, a familiar agency, physician) that foster connection. ○ Consider culture: Strong connection between alcohol use and Latino cultural/familial traditions and norms. <p>Strategies for connecting:</p> <ul style="list-style-type: none"> ○ Quickly establish why participation is important. ○ Demonstrate ongoing commitment to the community - “what kind of programs (to address alcohol use) are going to be created?” “Are you just going to take your sample and leave?”
Hope to Despair	<p><u>Summary:</u> <i>Participants voiced mixed feelings regarding the potential for more inclusive genetic research on alcohol use. There was optimism, tempered with pessimism.</i></p> <hr/> <p>Optimism:</p> <ul style="list-style-type: none"> ○ There was hope for a greater sense of equality via research, and that once Latinos understood the importance of research, they would readily be willing to “pitch in”. <p>Pessimism:</p> <ul style="list-style-type: none"> ○ Latinos would be highly skeptical of any research request, but especially leery of research involving genetics and would largely flat-out refuse participation. <p>Fostering hope:</p>

Theme	Relevant Content from Latino Focus Groups <ul style="list-style-type: none"> ○ Discuss the impact and utility of your work - “Tug at our heart strings”; demonstrate “How can we break it [the cycle of addiction], so our kids don’t have to go through the same trouble – liver disease.”
Ease to Hassle	<p><u>Summary:</u> <i>Participants emphasized the need to consider convenience, that requests for research participation take place in the context of very busy lives.</i></p> <hr/> <p>Place:</p> <ul style="list-style-type: none"> ○ Preference is for studies to “catch me where I already am”, such as doctor’s office or health fair. “We (the Latino community) are not inclined to do extra work.” <p>Significance:</p> <ul style="list-style-type: none"> ○ Desire to receive information to stay informed about the study, but not to be pestered by too many updates. <p>Nature of participation:</p> <ul style="list-style-type: none"> ○ Type of study procedure matters – giving blood was seen as more of a hassle (vs. saliva), and online surveys were viewed as more convenient than mail and phone.
Benefit to Cost	<p><u>Summary:</u> <i>A variety of benefits appealed to participants, juxtaposed to some potential costs for participants in arriving at participation decisions.</i></p> <hr/> <p>Benefits:</p> <ul style="list-style-type: none"> ○ Incentives: Viewed as important and requiring thoughtful attention regarding size and timing (not first thing in recruitment, but early in conversation). ○ Information as benefit: Personal health information, information about alcohol use, information about the research and progress being made. <p>Costs:</p> <ul style="list-style-type: none"> ○ Personal: Being “labeled forever” (by research findings), “someone knowing all about me”, no results from tests of biological samples. ○ Community: Research being used to restrict access, such as denying insurance benefits to people with similar characteristics.
Experience to No Experience	<p><u>Summary:</u> <i>An emergent theme identified as significant for participants in this study was previous exposure to either participation in research or having requests for biological samples (for non-research purposes).</i></p> <hr/> <p>Prior research participation:</p> <ul style="list-style-type: none"> ○ Most participants did not have prior research experience. Participants emphasized that they would be more likely to participate in research if they or a family member were directly affected by the disease/condition being studied. <p>Previous biological sample collection:</p> <ul style="list-style-type: none"> ○ Many participants had previously provided biological samples (e.g. doctors, justice system requirements). These carried many affective connections for participants. For example, one participant felt a strong sense of purpose related to donating blood, because he knew that his blood type was particularly useful. As another example, one participant had a negative association with providing biological samples because he had provided them as part of justice system requirements.