
Investigating the Lack of Minority Representation from the
Latino/Hispanic Community in Biomedical Research through the
Analysis of Community Seminars to Encourage Involvement

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Why does this matter?

- The Hispanic community is not well-represented in biomedical research (Ceballos, 2014)
- According to the latest US Census, by 2060 the Hispanic community will represent 26% of the US population (US Census, 2018)
- Increase knowledge and health outcomes for minority populations
- Address barriers or concerns about biomedical studies to increase retention for diverse population in research studies

Background Information: Past Year FG Themes

Barriers

- Personal Obligations and responsibilities
- Feelings of being powerless
- Distrust

Benefits

- Seek knowledge
- Desire to be healthy
- Health improvement of the community as a whole

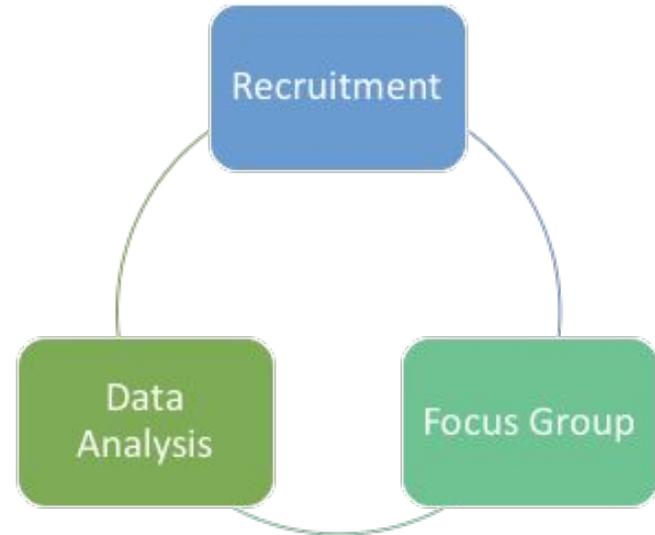
Research Questions

How do Latino communities in Orange County feel about participating in biomedical studies?

- What are Latinos' **concerns/feelings** when research studies request medical information?
- What can **hinder** potential minority participants **from participating** in biomedical research?
- What can researchers do to **increase participation** in biomedical research?

Methodology

- Recruitment
 - Participants from UCI Family Health Clinic in Santa Ana, CA
- English-Speaking Focus Group
 - 4 women, 2 men
- Spanish-Speaking Focus Group
 - 3 women
- Data Analysis



What is a Focus Group?

Objective: to give the researcher an understanding of the participants' perspective on the topic in discussion.

Focus group discussion:

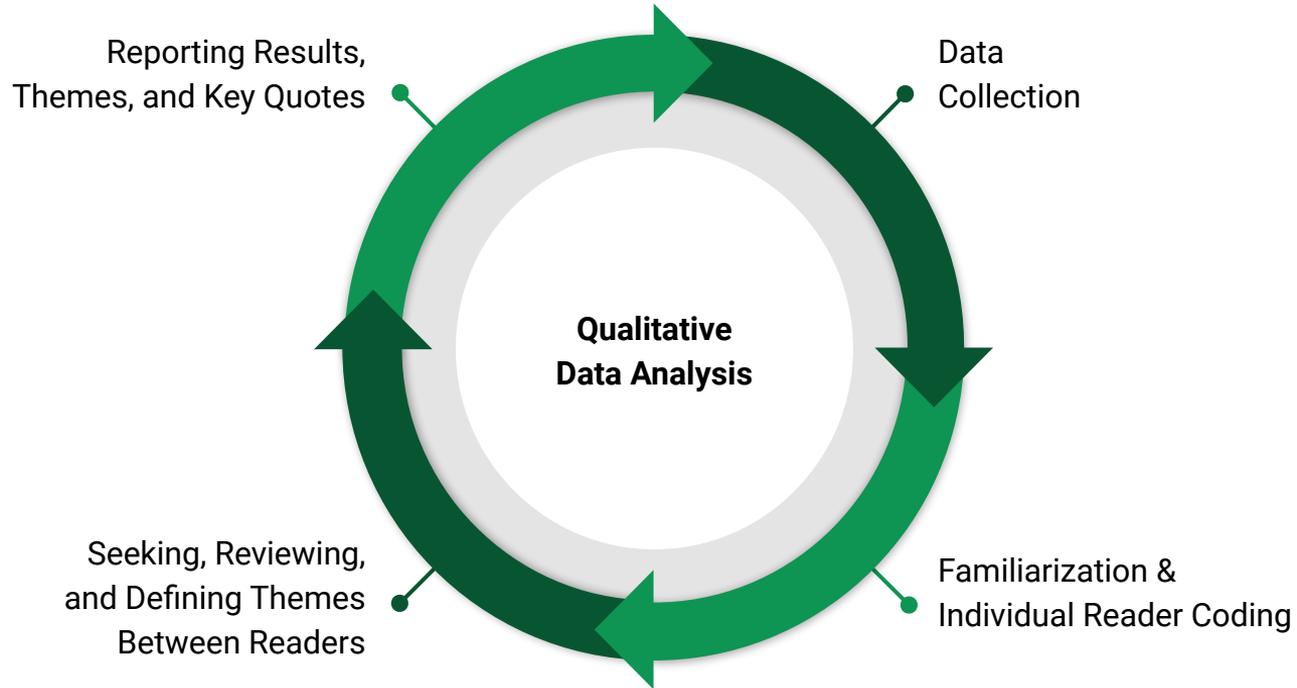
- small group of participants gather to discuss a specified topic or an issue to generate data
- interaction between the moderator and the group

Benefits:

- Useful to confirm or discover meaning, research barriers, or concerns
- Compare or enhance previous focus groups findings



Data Analysis



Demographic Information: Focus Groups

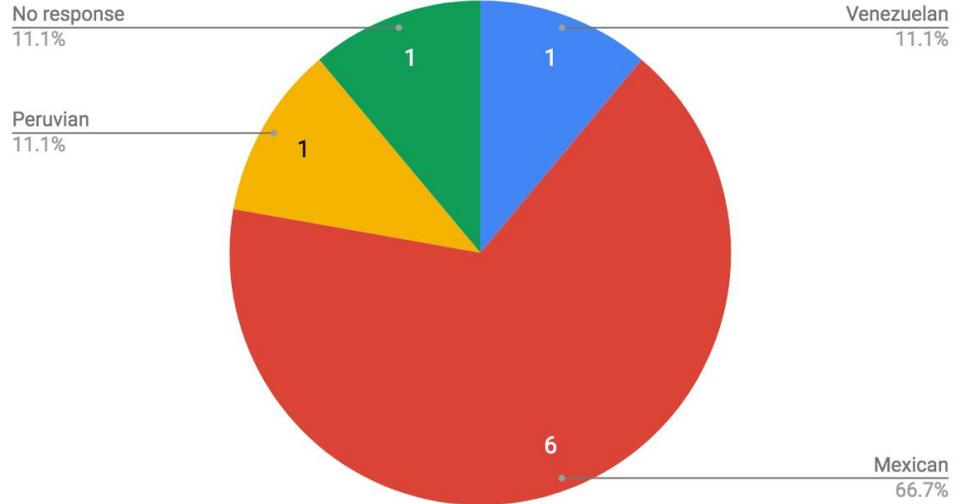
Total Participants: 9

Gender: Female(7): Male(2)

Mean Age: 52.4 years

Percentage of Non U.S. Born: 89%

Ethnicity



Preliminary Findings: Central Themes

Structure of Care & Research

Lack of Communication

Lack of Connection between
Patient and Doctor

Barriers to Research Participation

Mistrust and Safety Concerns

Cultural barriers

Motivating Factors

Learning about Individual
Health

Next Generation

Lack of Communication



“Rather than helping me, the study harmed me. In what manner will the researchers, doctors, or **whoever it is will they help me since I was harmed?**”

- Maria

Lack of Connection

“...my family and I] come and one doctor will see us and then they leave and we will get another doctor. After that **we do not know who our doctor is, so then we get confused**... That is a problem... because we will come and the doctor that helped us will no longer be here... So that makes it difficult.”

- Julia

Mistrust

“Probably because one does not participate much in these types of medical studies is because **we don't know what the following studies will do to us** ... We don't know what they will do after having the results, where they will implement them, what will happen with all the research.”

- Rosa

“We're like the **forgotten culture**. Nobody cared about us. And now they're like focusing on us.”

- Jose

Safety Concerns



“People are wary. We are Latino ... people were afraid ... they might take you to ICE, or something. Remember that there are people who are **afraid**, the ignorance, that something will happen.”

- Jose

“...the **government is scaring the community** to do the names, address, phone number ... What about blood pressure numbers [and blood examinations] or that kind of information? [People in my community] think what are [researchers] gonna do with my data?”

- Dolores

“Yeah, or even trouble ... they have **family that you can be deported** ... I mean it's hard times right now.”

- Jose

Cultural Barriers

“Many times we come from communities very... distrustful... my husband...told me why you come?... ‘you came to serve as **guinea pigs.**’ ”

- Maria

“**People want precaution**...they come to places like this because, ‘Oh, you wanna make some money? Come over here!... Lot of people are afraid to come to something like that.’ ”

- Jose

Learning About Individual Health

“Many people don’t know what they get and what they have and they end up getting stuff that they know nothing about...”

- Julia

“But **people want to understand why...** people why wonder Latinos are more accessible to diabetes than a normal... and it’s something that we could learn to by or what we could prevent too.”

- Jose

“You need to explain well to the people what is the **motive** of the study, what **benefits** it will bring in the future, Also **bring examples** from other studies...”

- Rosa

Next Generation

“What I find interesting are the things that us Latinos may not know. I am Mexican, and in Mexico people are dying and people do not know why. People will say that other people die, because they were really old and it was their time, but it also could have been because they had a disease and they did not know about it. So that’s why I find it interesting to **learn about diseases** that we don’t know about and **how to treat those diseases** as well.”

- Isabel

“She’s not doing this for herself, [she] wants to do this to... help the future kids, grandkids, future generations so that the **problems we have right now ain’t gonna affect them.**”

- Jose

Findings Summary

Negatives:

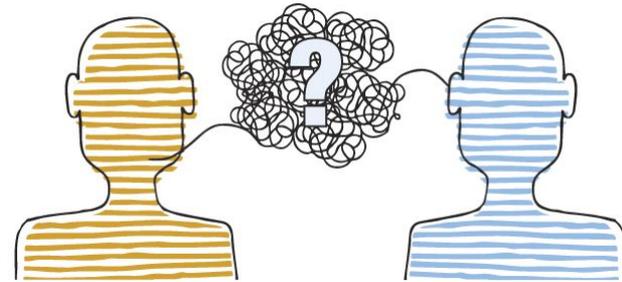
- lack of **communication**
- lack of **connection**
- **mistrust**
- **safety** concerns
- **cultural** barriers

Positives:

- Learn about **individual health**
- Improve health for **future generations**

Limitations

- Small Sample Size
- Population Limited to Clinic Patients
- Age Range of Participants
- Language Barrier



Future Directions

Recruitment:

- Recruit beyond UCI Family Health Center in Santa Ana
- More Participants per Focus Group
- Focus Groups with Younger Participants

Focus Groups:

- Verify Preliminary Findings in Future Groups
- Vary Time and Location Held
- Continue Offering both English and Spanish
- Extend research methods



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References

- Arar, Nedal H, et al. "Ethical Issues Associated with Conducting Genetic Family Studies of Complex Disease." *Annals of Epidemiology*, U.S. National Library of Medicine, Oct. 2005, www.ncbi.nlm.nih.gov/pubmed/16157258.
- Ceballos, Rachel M., et al. "Latino Beliefs About Biomedical Research Participation: A Qualitative Study on the U.S.–Mexico Border - Rachel M. Ceballos, Sarah Knerr, Mary Alice Scott, Sarah D. Hohl, Rachel C. Malen, Hugo Vilchis, Beti Thompson, 2014." *SAGE Journals*, journals.sagepub.com/doi/10.1177/1556264614544454.
- Katz, Ralph V, et al. "Participation in Biomedical Research Studies and Cancer Screenings: Perceptions of Risks to Minorities Compared with Whites." *Cancer Control : Journal of the Moffitt Cancer Center*, U.S. National Library of Medicine, Oct. 2008, www.ncbi.nlm.nih.gov/pmc/articles/PMC2702154/.
- Ulrich, Angela, et al. "Issues in Biomedical Research: What Do Hispanics Think?" *American Journal of Health Behavior*, U.S. National Library of Medicine, Jan. 2013, www.ncbi.nlm.nih.gov/pmc/articles/PMC3860276/.
- Umaña-Taylor, Adriana J., and Mayra Y. Bámaca. "Conducting Focus Groups with Latino Populations: Lessons from the Field." *Family Relations*, vol. 53, no. 3, 2004, pp. 261–272. *JSTOR*, www.jstor.org/stable/3700344.
- US Census Bureau. "Hispanic Population to Reach 111 Million by 2060." *Hispanic Population to Reach 111 Million by 2060*, 4 Oct. 2018, www.census.gov/library/visualizations/2018/comm/hispanic-projected-pop.html.
- Wong, L P. "Focus Group Discussion: a Tool for Health and Medical Research." *Singapore Medical Journal*, U.S. National Library of Medicine, Mar. 2008, www.ncbi.nlm.nih.gov/pubmed/18363011.

Any Questions?

Methodology: Focus Group Guide

1) Think back to a time when you said no to participating in a medical research study...What were some of your concerns or reasons for not joining?

Probe: Do you think that your family and friends would express these same concerns?

2) If you were to participate in this research, what would you hope to gain? Why would you participate?

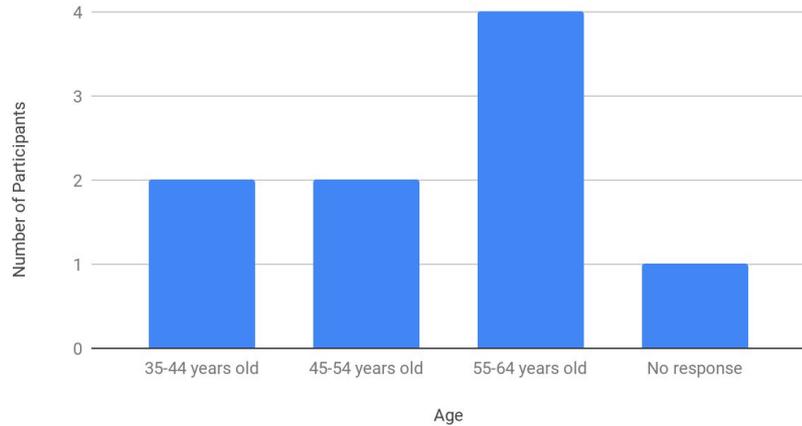
Probe: Are there specific aspects of the research that you feel you could benefit from?

3) How would you feel if you were asked to provide blood and urine samples to researchers?

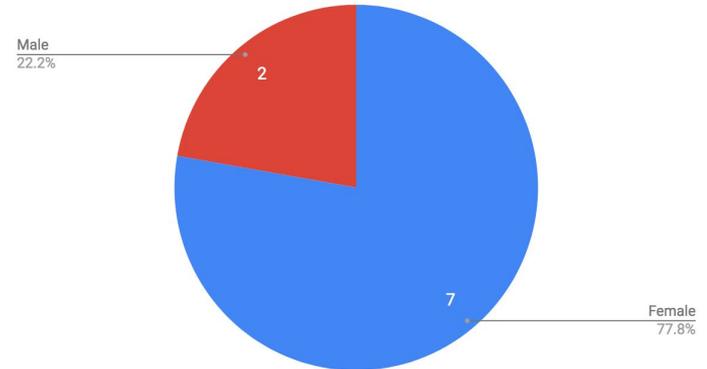
Probe: Have you provided these kinds of samples before for a study? What made you feel comfortable or uncomfortable to provide samples?

Focus Group Demographics: in Detail

Age Distribution

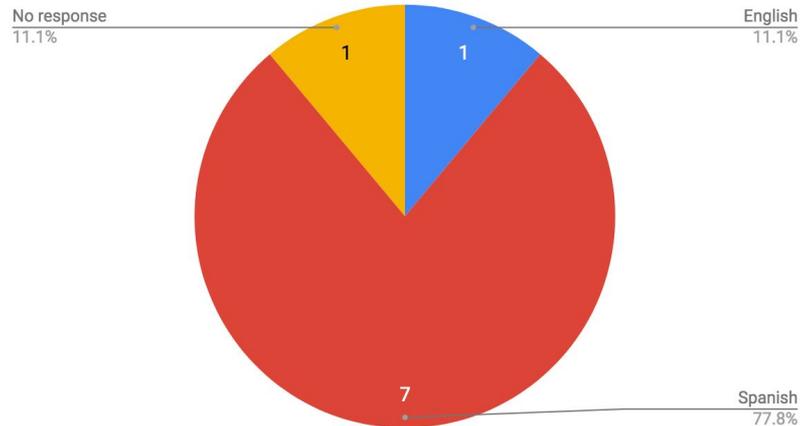


Gender Distribution

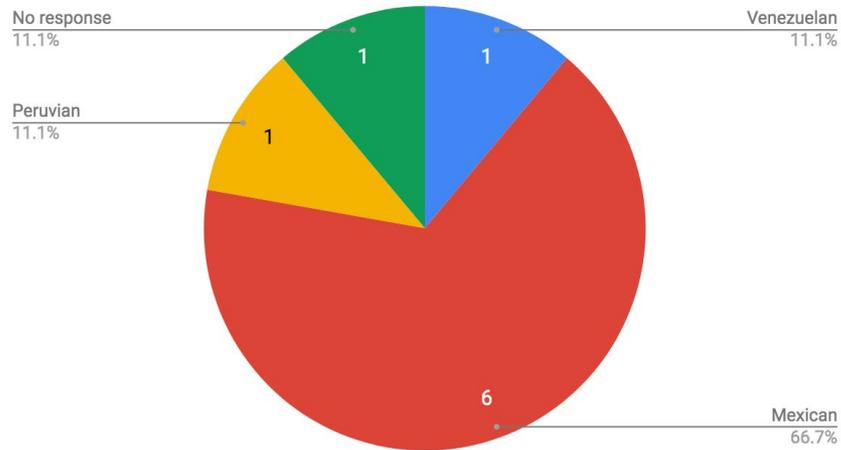


Focus Group Demographics: Cultural Background

Language Spoken at Home

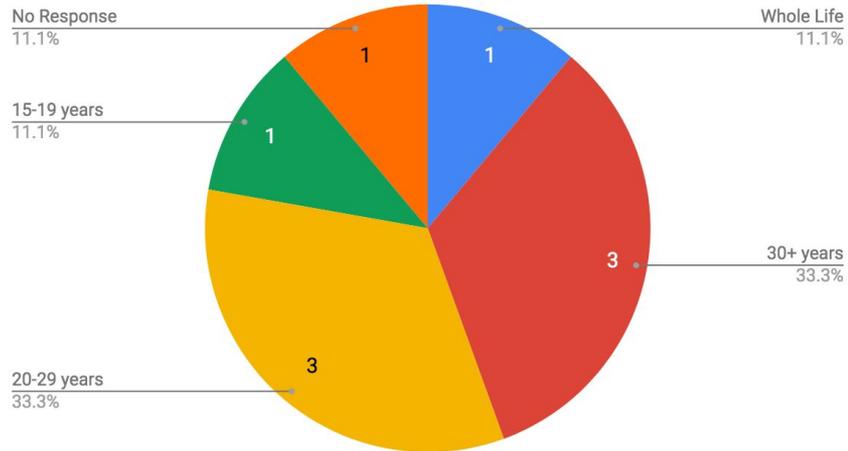


Ethnicity



Focus Group Demographics: Acculturation Factors

Years in the United States



Level of Education

