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# Community perspectives on biobanking:

A qualitative study among Mexican-origin community members living in three Texas cities

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## APHA ROUNDTABLE

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### Learning Areas:

- Assessment of individual and community needs for health education
- Diversity and culture

### Learning Objectives:

- Explain the results of a qualitative study of Mexican-American community member views on biobanking and biospecimen donation.

**Abstract:** Population-based biobanks are important for identifying the causes and mechanisms of diseases and can contribute to more accurate diagnosis, treatment, and prevention. The usefulness of biobanks depends on the donation of specimens from individuals of diverse racial and ethnic communities; however, only a small percentage of current participants are Hispanics/Latinos. We present the results of a qualitative study to assess biobanking knowledge and attitudes of Mexican-origin community members living in three Texas cities, as well as their opinions on barriers and facilitators to participation.

**Methods.** We conducted 15 focus groups, 8 in Spanish and 7 in English, with a total of 128 individuals. We transcribed the recorded data, and coded and analyzed the transcripts using Atlas.ti v. 7.0.

**Results.** The majority of participants reported that they had never heard of biobanking and they were confused about what specimens would be collected. Most participants expressed a willingness to participate in biobanking to benefit society, family members, and science, especially because they felt that donation did not present a major risk to themselves. However, participants reported that they needed to understand the details of participation, such as how long specimens would be stored, before they would agree to donate their biospecimens.

Participants expressed a need for education in their community about the societal benefits that can emerge from biobanking.

**Discussion.** These results can be used to develop appropriate educational materials and strategies to increase biobanking participation in this community.

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## Importance of Hispanic inclusion in biobanking

- Biobanks are repositories for biological samples (i.e. blood, saliva) that are collected and stored for research purposes.
  - Biobanks are important for identifying the causes and mechanisms of disease, and contribute to earlier, more accurate prevention, diagnosis, and treatment.
  - Biobanks' usefulness depends on inclusion of diverse racial and ethnic communities to ensure the generalizability of the results.
  - Hispanics represent less than 1% of the specimens collected by 7 biorepository facilities in U.S and less than 2% of participants in genome-wide association studies.
  - There is a need to further investigate factors influencing biobanking participation among Hispanics and Mexican Americans (the largest sub-group).
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## Results

We conducted 15 focus groups with 128 Mexican origin adults in Houston, El Paso and Brownsville, TX to explore factors influencing willingness to participate in biobanking. Individuals were primarily low-income, uninsured, with less than a high school education.

The following themes emerged:

### Barriers

- Lack of knowledge and information

*"I also think that it's because there is not much information, that is, there aren't programs that tell you about this."*

- Lack of personal benefit

*"Because we don't gain anything, like they said. They aren't going to tell us if we have something, so why do it?"*

- Fear of pain or harm

*"I don't donate blood anywhere. It's not that I don't want to it's just the needles."*

- Feelings of distrust

*"If you donate them, they're still going to take them and maybe do whatever they want, and you're not even going to know about it."*

- Language barriers

*"If they didn't [have the right resources], then it wouldn't – I wouldn't recommend Hispanics do it, because it seems like they'd probably be taking advantage"*

### Facilitators

- Altruism and advancing science

*"It's like helping science. Not today, but in the future it can help."*

- Sufficient understanding

*"Of course I would only [donate] if I was truly informed, so that I felt safe."*

- Personal benefits

*"Or I also think, for example, that they do these studies and they ask people 'do you want to know the results of this exam we are doing'. If the person says yes, then ok, they should give it to them."*



- Perception of minimal risk

*"That's all right. It's something that we reproduce. It's like something that we can redo again, you know?...It's like saliva or something. You could live without it. And if it's going to help or better or improve somebody else, why not?"*

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## Recommendations



Participants recommended:

- Education in the Hispanic community about the existence and purpose of biobanks
- Make participation easier by accommodating work schedule, etc. and compensating participants
- Having Spanish-language staff and materials
- Using recruitment strategies such as in-person discussions that are more appealing than less personable (i.e. flyers) recruitment strategies

**Overall:** Researchers need to reach out to the Hispanic community to educate and go to their spaces to recruit.

*"I say that more than anything its communication, to inform the community what it is for, what would be taken, where it was going to be used, and how it can benefit us in the future."*