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).
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.”

**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.”

**Results**

- 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”
- 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?”

**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.”