

# Conversations with Community about Biomarker Research

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# Today's Challenge

Can we increase the number of participants from under-represented minority communities in research that includes collection of biomarkers?

# Historical Context

- Well-known examples of unethical research in minority communities
- Discordant relationship between biomedical investigators and these communities
- Under-representation of certain groups in biomedical research, including clinical trials

## Insights from Previous Work

- Engage UC
  - Collaboration across UCs to consider governance for biobanks
- Gerardo Moreno, UCLA Assistant Professor
  - Focus groups with older Latinos and African Americans

## Engage UC

- Exploring ways to improve ethical stewardship of biobanks
- Dialogues held using Deliberative Community Engagement methods in San Francisco & Los Angeles
- Stakeholders included UC patients and research volunteers

# Key Comments

- Transparency critical
  - Details about how specimens are stored (pictures, location, etc)
  - Specifics about long-term storage and how decisions are made about the use of specimens
- Delve into the consent process
  - Evaluating community-informed consent system
  - Multimedia approaches to educating potential contributors

# Opinions of Older Adults

- Focus groups & structured interviews conducted with Latino and African American older adults
- Partnered with LA CAPRA and RCMAR/CHIME
- Topics focused on biomarker research
- Used framework from Ford (2008) regarding barriers and facilitators
  - Awareness
  - Opportunity
  - Acceptance/Refusal

# Opinions: Awareness

## Barriers

- Language
- Health literacy
- Cultural knowledge & beliefs
- Education

## Facilitators

- Personal health
- Previous participation
- Knowledge  
(Transparency)
- Cultural sensitivity



# Opinions: Opportunity

## **Barriers**

- Communication
- Professionalism
- Costs & trade offs
- Specimen collection burden

## **Facilitators**

- Protocol characteristics
- Consent forms
- Study staff from community
- Outreach/team visibility
- Community leaders

# Opinions: Acceptance

## **Barriers**

- Mistrust
- Fear of bio-specimen collection
- Perceived harms
- Competing demands
- Transportation

## **Facilitators**

- Incentives
- Altruism
- Family / community
- Perceived benefits

## LA SPIRP

- SPIRP focus provides a rich context to explore this
- Collaboration of Biomarker and Community Engagement Cores
- Identified biomarkers of interest
  - BMI, BP, Lipids, CRP
- Held conversation at 2014 Community Symposium

## Biomarker Conversation

- Reviewed draft discussion items with Community Advisory Panel
- Developed slides to guide discussion
- Planned to hold one group in English & one in Spanish, but scheduling changes ended up in one combined group

## Discussion Goal

Goal presented to group:

Develop educational materials to:

1. Increase community knowledge and understanding about the importance of biomarkers.
2. Increase community willingness to participate in research that includes biomarkers

## Discussion Topics

1. What is a biomarker?
2. Ask your advice about how we can develop educational materials that explain:
  - a) what biomarkers are
  - b) how they are related to your health
  - c) why they are important in research on health
  - d) what is involved if you agree to collection of biomarkers as part of a research study
3. Ask for your suggestions about what other information you think is needed?

## 2c. Why are biomarkers important in research?

Better understanding of biomarkers needed to help communities and health care providers work together to improve health and well-being

# Including biomarkers in research can

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- Help us better understand how difficult life experiences (e.g., stress, grief, other difficulties) influence our health





# Including biomarkers in research can

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- Allow us to identify other important biomarkers (e.g., stress hormones)



# Including biomarkers in research can

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- Help test for new and better ways to change biomarkers to improve health (e.g., lowering blood pressure)



Do these reasons encourage you to participate in research?

Why or why not?

What else would it be important to say?

# Community Members' Suggestions

- Precise language is important (“biomarcadores” vs “marcadores biológicas”)
- Educate me – help me learn more about my health (eg, Why are there 2 numbers for BP?)
- Tell me my numbers, even if you are not sure yet what they mean
- Tell me about my specimen, where it is stored and who is going to use it

# How We Are Using This Information

- Staff Training
  - Educate staff about the purpose, meaning, and process for collecting biomarkers
- Transparency
  - Devices are easy; still need to decide about DBS assays
- Community partnership
  - Built in to the design of the Center and the projects
- Collection burden
  - Fingerprick usually more tolerable than venipuncture

## There Is More to Do

- Education materials
  - Can be costly – and need to be weighed against the other information being provided to the potential participants
- Further work with ethicists & clinicians talking with community
  - Providing information without known health consequences or course of action
- Continuing to ask what problems different communities want to address