

# Challenges and Opportunities for Sustaining Community Engagement and Partnerships in Genomics Research

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# DISCLOSURES

- Consultant for 23andMe
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# Barriers to Sustaining Community Engagement

## Organizational – Lack of cultural sensitivity

- Research and recruitment teams should have representation that is similar to the group that is being solicited for participation in genomics research

## Structural –Continued Participant Engagement

- Develop strategic partnerships with organizations of interest

## Project design- Interest of target audience vs. interest of researcher

- Target audience engaged in complete R&D process from beginning to final product
- Find alignment for both parties to deliver mutual benefit

# Engagement to Build Relationships & Trust

## Be present/Show Up

- In-person, on-line, radio, etc.

## Be transparent

- Express goals on front end
- Give participant control on involvement level

## Be Respectful of participants' time

- Offer payment for participation

## Be True

- Do what you say you're going to do

## Listen

- Participant concerns over release of PHI/data

# Lessons Learned

## Be patient, it takes time

- Negative historical experiences with research remain a prevalent barrier to participation

## Participants have concerns in the areas of:

- Legal
  - Participants fear information could be reported to law enforcement
- Cloning
  - Provide disclaimer on use of genomic information
- Exploit data for financial gain
  - Provide mutual benefit for both parties