Authentic Engagement with Communities to Address COVID-19 Disparities

Advancing Anti-Racism and Health Equity in a Lingering Pandemic

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I have no disclosures.
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• Tara Vijayan
• Stefanie Vassar

• MANY Community Partner Organizations
• LA County Department of Health Services
• LAC Department of Public Health
• CA DPH
• COVID-19 Community Consultant Panel

Partnering Community Organizations, Stakeholders, and Individuals from across California with: UCLA • SDSU • Scripps Stanford • UCD • UCI • UCM • UCR • UCSD • UCSF • USC

CalGovOps

NIH

National Center for Advancing Translational Sciences

NIH CEAL

Community Engagement Alliance

UCLACTSI

Grant #UL1TR001881
Objectives

Strategies to combat disparities throughout the COVID-19 pandemic

• Vaccine development: COVID-19 Community Panel
• Vaccine mis/disinformation, hesitancy, deliberation: CEAL Alliance
• Vaccination rates: Get Out The Vaccine
Disparities in Diverse Communities in CA

- **Death rate for Latino people is 19% higher than statewide**
  - Deaths per 100K people:
    - 195 Latino
    - 164 all ethnicities

- **Case rate for Pacific Islanders is 43% higher than statewide**
  - Cases per 100K people:
    - 15,588 NHPI
    - 10,886 all ethnicities

- **Death rate for Black people is 14% higher than statewide**
  - Deaths per 100K people:
    - 186 Black
    - 164 all ethnicities

- **Case rate for communities with median income <$40K is 33% higher than statewide**
  - Cases per 100K people:
    - 14,460 income <$40K
    - 10,886 all income brackets

Note: This data is cumulative since the first COVID-19 case was reported in January 2020. Case rate is defined as cumulative COVID-19 cases per 100K population. Death rate is defined as cumulative COVID-19 deaths per 100K.
Summer/Fall of 2020: COVID-19 Myths and Misconceptions

COVID-19
- It won’t happen to me
- Masks are unhealthy
- Youth are not at risk for COVID-19
- COVID-19 will be no worse than seasonal flu
- Wealthy elites started COVID-19 for profit
- Natural immunity is best, the body can protect itself from COVID-19
- Vitamin C is an effective prevention

Vaccines
- Can alter your DNA
- 5G Mobile phone can transmit coronavirus
- Faked results
- Can get COVID from the Vaccine
- Nanosensors to monitor your location
Lack of Diversity in COVID-19 Vaccine Trials: Moderna COVE Trial vs. US Population

How do we improve representation in the COVID-19 vaccine trials at UCLA?
Principles of Community Engagement

• Careful Planning and Preparation
• Inclusion and Demographic Diversity – adequate representation
• Collaboration and Shared Purpose
• Openness and Learning
• Transparency and Trust
• Impact and Action – shared vision of what you want to accomplish
• Sustained Engagement and Participatory Culture – partner with researchers who work with the community and maintain the relationships

Modified from: "Core Principles for Public Engagement." National Coalition for Dialogue and Deliberation (NCDD), International Association for Public Participation (IAP2), and the Co-Intelligence Institute, 2009.
COVID-19 Community Consultant Panel
Los Angeles COVID-19 Vaccine Trials

Deliberative Community Engagement (DCE)
- Qualitative research method designed to obtain opinions from lay individuals on complex topics with which they are unfamiliar

EXPERTS:
- UCLA Clinical and Translational Science Institute (CTSI)
- Clinical Trial sites (UCLA CARE Center, Lundquist/ Harbor-UCLA Medical Center, UCLA Vine Street Clinic)
- Community Stakeholders who reflected the racial/ethnic and socioeconomic diversity of LA County
## CCP Recommendations / Considerations

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<td><strong>Enhance accessibility of the trial:</strong></td>
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<td>• Provide transportation for trial participants</td>
<td>• Additional funding identified to provide transportation for clinical participants (both routine visits and “sick day visits”).</td>
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<td>• Health care for uninsured participants if adverse reactions/COVID-related illness</td>
<td>• Detailed information on participant coverage for adverse reactions through the trial</td>
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<td>• Increase trial sites in minority communities</td>
<td>• Recommended community clinics, mobile trial sites</td>
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<td>• Cultural competence &amp; customer service</td>
<td>• Participants should be welcomed, asked their gender pronouns, shown the restrooms, given food and drink, and be thanked</td>
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Understanding COVID-19 Vaccine Decision-Making in Multi-Ethnic Communities

- Focus groups: Latino, Black, American Indian, Filipino, and Pacific Islander
- Majority (73%) resided in **high poverty zip codes** or were **essential workers**
Themes in COVID-19 Vaccine Decision-Making

Misinformation, Disinformation, Concerns

“Things sound ... crazy but they are understandable ..., people don’t trust the vaccine because they think it’s going to genetically alter their body in some way..., like they will become sterile or have some kind of implanted chip that along with the 5G antennas.”
—Latino participant

“These chain emails and Facebook Messenger, and Viber Messenger, about it’s not a pandemic, how to cure it with like lemon salt water... my concern is that my family are getting all this bad information from the Philippines and then not listening to our doctors over here.”
—Filipino participant

“The...neighborhood leaders... they’re all saying, no, they think that COVID is a hoax, that it’s not real.... The government, the city, the state, they don’t trust them... No one is coming around to address ...health issues or anything with them. So they’re like “Why should we care about jumping in line getting a vaccine when we’ve been ignored, we’re being ignored?”
—Black/African American participant

“There’s certainly ... that general feeling among indigenous peoples that a lot of times research hasn’t been with the benefit of those people in mind. In fact, almost the opposite.”
—Pacific Islander participant
Themes in COVID-19 Vaccine Decision-Making

Vaccine Equity: Accessibility, Affordability, Representation

“We hope we get same vaccine that the healthcare staff are getting.”
–Latino/a participant

“Our incarcerated community members... elders... the foster care system. We can't forget about them.”
–American Indian

“What phase are the undocumented in?”
–Latino/a participant

"Filipinos can get lost in the system because... the language barriers and... just not knowing how things work."
–Filipino/a participant
Key Takeaways

• Vaccine hesitancy is a complex, multifaceted concept that encompasses deliberation, accessibility, and acceptability.

• Reduce structural barriers in parallel with vaccine outreach and engagement.

• Collaborate with, invest in, and empower trusted community leaders to share information and provide navigation support.

• Need for representation and data transparency for all high-risk groups to communicate vaccine effectiveness (race/ethnicity, age, chronic disease).

• Desire to dispel misinformation from social media in US and abroad to support informed decision-making.

• Mistrust is based on historic and contemporary mistreatment. Show empathy, understanding and respect to communities.
• Statewide community engaged partnership addressing COVID-19 in high-risk communities.

• Funded by the NIH Community Engagement Alliance (CEAL) Against COVID-19 Disparities

• 11 academic institutions and >75 community partners

**Trusted Education/Outreach**

• CHWs

• CBOs

• Local Media / Ethnic Media

**Qualitative Research**

• Focus groups in multiethnic communities

• Deliberative community engagement

• Health Fairs, town halls, listening sessions

**Capacity Building**

• Training (CHWs, Media)

**Surveys / needs assessments**

• Surveys

• CHIS

**Populations / Communities**

• Latinx; Black; Asian (Filipino, Chinese, Vietnamese, Korean); Native Hawaiian; Pacific Islander; American Indian

• Essential Workers (farmworkers, service workers, etc.)

• Immigrant

• LGBTQ

• Low-income
Outreach Materials Derived from Focus Groups

- Addressed misconceptions and information gaps
- Highlighted diversity in clinical trials
- Broad dissemination of materials and lessons learned from focus groups to community, on-the-ground leaders, and policy makers

Weighing the Risks: Infection vs. Vaccination

Every million COVID-19 vaccinations

- ~2-3 serious reactions
- ~1-2 hospitalizations
- 1-2 deaths under investigation

COVID-19 Vaccine Information: Answers to Important Questions!

Pfizer & Moderna January 2021

Why should I get vaccinated?

For your family, and to stop the spread, protect your community, and increase your risk of long-term complications.

Is the vaccine safe for someone like me?

Over 70,000 people participated in Pfizer and Moderna trials and were equally safe for all:
- Adults, all ages (85+, over 95% effective)
- Racial/ethnic groups (Black, Latino, other communities of color, over 95% effective)
- Chronic conditions (about 90% effective)

Even if you had COVID-19 already, the vaccine is safe and can protect your immunity.

How many people from racial and ethnic groups were part of the clinical trials?

Modern and Pfizer clinical trials included a broad range of diverse participants: American Indian (0.8%, 0.6%), Asian (4.7%, 4.4%), Black (9.7%, 9.0%), Hispanic/Latino (20.5%, 26.2%), and White (69.2%, 70.4%).

Vaccine Effectiveness: Race/Ethnicity Data

- Moderna Covid Vaccine Trials
  - 94.1% Effective Overall
  - 93.5% Effective in People of Color

- Pfizer Covid Vaccine Trials
  - 95% Effective Overall

Which vaccine choice?

- Both Pfizer and Moderna vaccines are about 95% effective.
- At this point, do not choose only vaccines of the same age or gender.

Is the vaccine safe?

Not currently, but if you get the vaccine, it will increase your risk of complications.

Should I get the COVID-19 Vaccine?

Yes. Protection can prolong your life.
Since September 2020 Statewide STOP COVID-19:

- **300+** Town halls and community events, reaching over 120,000 community members
- **50+** Community health workers (CHWs)/promotoras trained in COVID-related information dissemination
- **125+** News features (i.e. TV, newspaper, radio, and ethnic media outlets)
- **13** Collaborations with COVID-19 vaccine clinical trials
- **40+** Focus groups
- **7** Policy Briefs
- **2** Academic publications: 2 published, 1 in-press, 2 submitted and ~10 in preparation

STOP COVID-19 CA: The COVID-19 California Alliance

First Samoan Congregational Christian Church of San Diego
Get Out the Vaccine (GOTV) State of California Initiative for Vaccine Registration

Goal: Reduce structural barriers to COVID-19 vaccine registration in areas with low vaccine rates, high COVID morbidity/mortality

- Partnership with 34 CBOs in Los Angeles and Central Valley
- Hire underemployed local residents as canvassers
- Register people for COVID-19 vaccination

Strategies
- Canvass door-to-door, text messages, phone calls
- Educate about COVID-19 vaccines using effective vaccine messaging
- Provide resources, connect to social services (rental relief, food insecurity, employment)
- Canvasser training: COVID-19, vaccines/therapeutics, countering mis/dis-information, accessible resources
Bidirectional Exchange in GOTV

Lessons learned from CBOs to improve implementation

• Fed back to us mis/dis-information on what they are hearing
• Creative strategies for engagement
• Lived experience + Personalized outreach and storytelling: “...why I understand your concerns, and why my story relates to yours...”
  • Esperanza Community Housing - 15 Canvassers
    • Lost 58 family members to COVID
    • 207 family and friends were diagnosed with COVID
    • 75 family members lost jobs

Esperanza Housing Corporation
Monic Uriarte
Director, Health Programs Canvassing Manager

Canvassers from Esperanza Community Housing 6/8/2021
Get Out The Vaccine Campaign (GOTV): Results to Date

As of October 2021

• **>800** Canvassers hired
• **2.3M** Doors canvassed
• **>500K** phone calls
• **>1.2M** text messages
• **>100k** conversations at events (crowd canvassing)
• **>48,000 individuals registered for vaccine**
To Address COVID-19* Disparities, and Reach Underrepresented Communities:

- Address challenges directly: time, appropriate funding
- Paradigm shift: “Hard to Reach” ➔ “Hardly Reached” (Keith Norris mantra)
- Listen to and learn from the community – both about what they are hearing and where they are hearing it from
- Share what we know and what we don’t know and recognize our own biases
- Non-traditional outreach that addresses needs while providing accurate information
- **Partner with the experts (academic and community)**
  - Existing centers that work with underserved communities - e.g., minority-serving institutions, CTSAs, RCMARs
  - Partner with the community: CBOs and individuals with deep knowledge and understanding who are trusted by the community

* ...or diabetes or hypertension or stroke or asthma or cancer prevention or preterm birth or ....
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