

Authentic Engagement with Communities to Address COVID-19 Disparities

RCMAR Alumni Lecture
October 18, 2021



I have no disclosures.

Acknowledgments

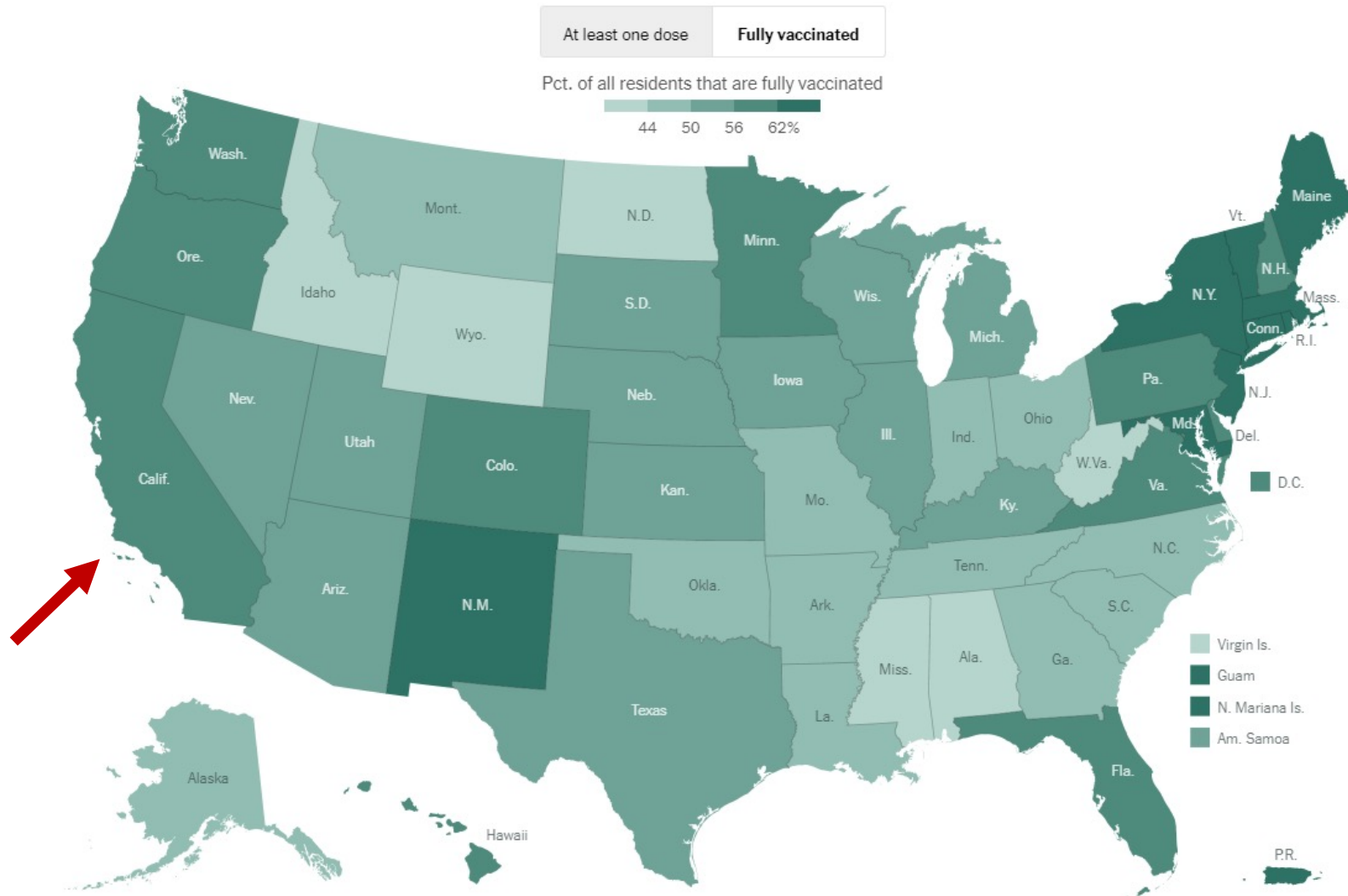
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- Stefanie Vassar
- **MANY Community Partner Organizations**
- **LA County Department of Health Services**
- **LAC Department of Public Health**
- **CA DPH**
- **COVID-19 Community Consultant Panel**



Objectives

- Examine COVID-19 disparities in California
- Discuss community engagement as a strategy to understand COVID-19 vaccine hesitancy, deliberation, and uptake in diverse communities
- Describe initiatives to mitigate racial/ethnic and socioeconomic disparities in COVID-19 vaccination in multi-ethnic communities

COVID Vaccinations by State



Name	Percent of people	
	Given at least one shot	Fully vaccinated
U.S. total*	64%	55%
Palau	98%	85%
Vermont	77%	69%
Connecticut	76%	68%
Maine	74%	68%
Rhode Island	75%	68%
Massachusetts	77%	68%
Guam	75%	66%
Puerto Rico	74%	66%
New Jersey	72%	64%
Maryland	70%	64%
New York	71%	63%
Northern Mariana Islands	66%	63%
New Mexico	72%	63%
New Hampshire	69%	61%
Washington	67%	60%
Oregon	66%	60%
Virginia	68%	60%
Washington, D.C.	70%	60%
Colorado	65%	59%
California	71%	59%
Minnesota	63%	58%
Pennsylvania	72%	57%
Hawaii	76%	57%
D.C.	68%	57%

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.

COVID-19 Vaccination Disparities in California

- California Department of Public Health has assigned every ZIP Code a **community health score** composed of economic and social indicators (*Healthy Places Index*).
- Vaccination rates vary widely by the community health score: the most **disadvantaged areas are 18 percentage points behind the highest ranking areas.**

Vaccinations in communities ranked by community health score

Fully vaccinated Partially vaccinated Not vaccinated

Lowest quartile



Second



Third



Highest

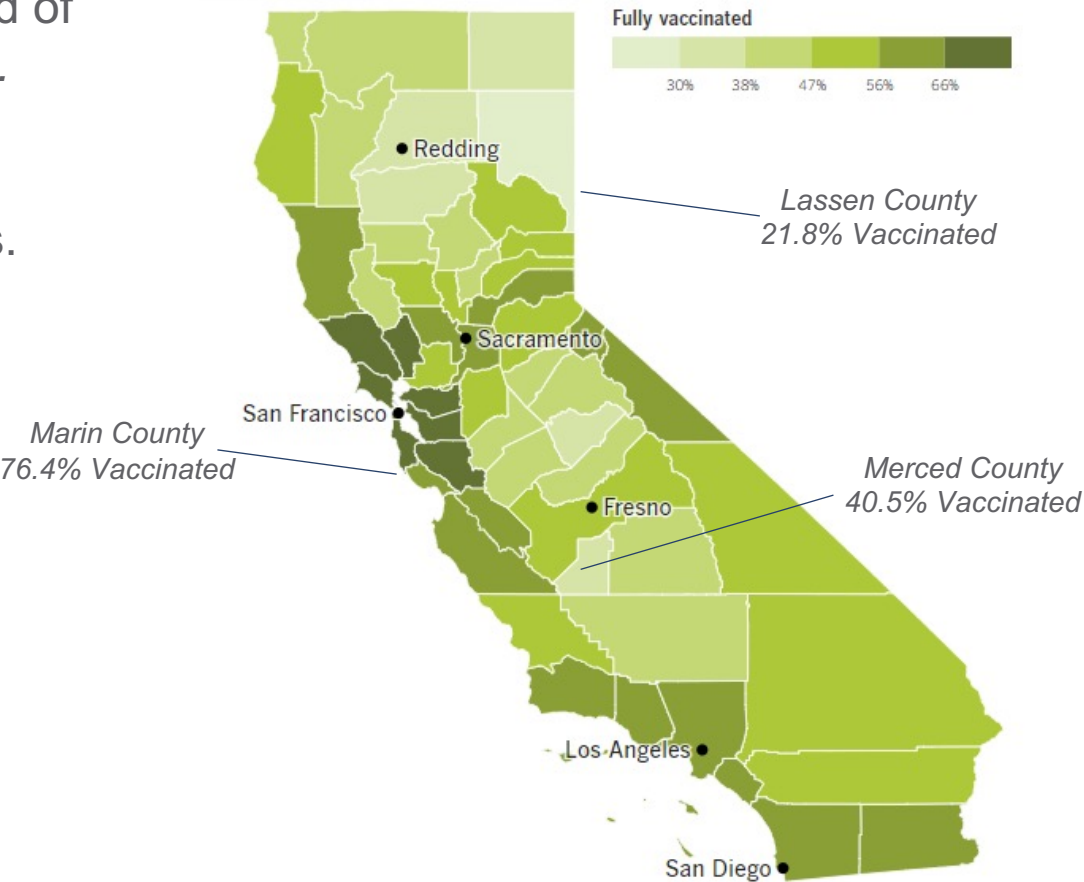


Vaccinations by county

The state health department publishes a breakdown of the number of residents fully and partially vaccinated in all 58 counties.

Progress

Fully vaccinated At least one dose

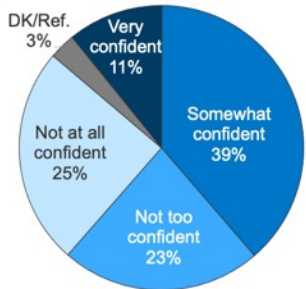


Summer/Fall of 2020: COVID-19 Myths and Misconceptions

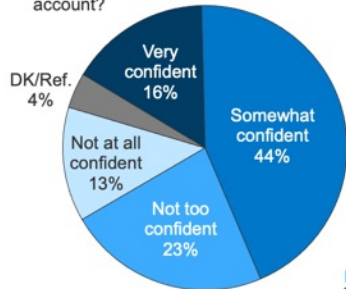
Figure 8

Many Black And Hispanic Adults Lack Confidence That Vaccine Development Process Is Taking Their Needs Into Account

AMONG BLACK ADULTS: How confident are you that the development of a coronavirus vaccine is taking the needs of Black people into account?



AMONG HISPANIC ADULTS: How confident are you that the development of a coronavirus vaccine is taking the needs of Hispanic or Latino people into account?



SOURCE: KFF COVID-19 Vaccine Monitor (KFF Health Tracking Poll, Nov. 30-Dec. 8, 2020). See topline for full question wording.

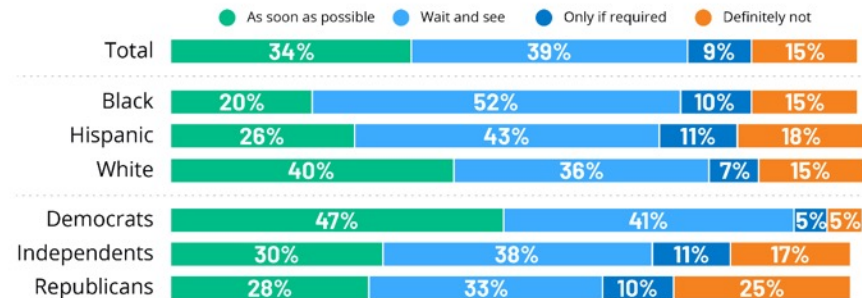
KFF COVID-19 Vaccine Monitor

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*

Republicans and Black Americans More Likely to Be Hesitant About Getting COVID-19 Vaccine

Percent of the public who fall in each group by COVID-19 vaccine enthusiasm:

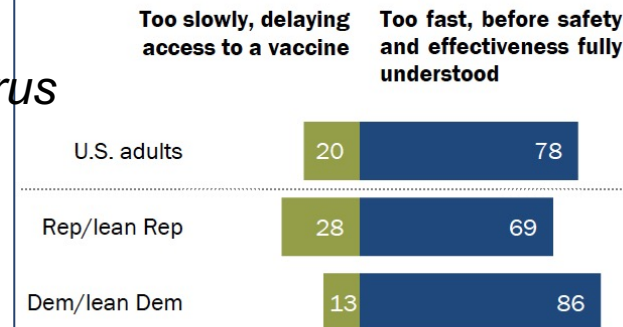


Vaccines

- *Can alter your DNA*
- *5G Mobile phone can transmit coronavirus*
- *Faked results*
- *Can get COVID from the Vaccine*
- *Nanosensors to monitor your location*

Public concern over moving too fast on COVID-19 vaccine approval process

% of U.S. adults who say they are more concerned that approval of a COVID-19 vaccine will move ...



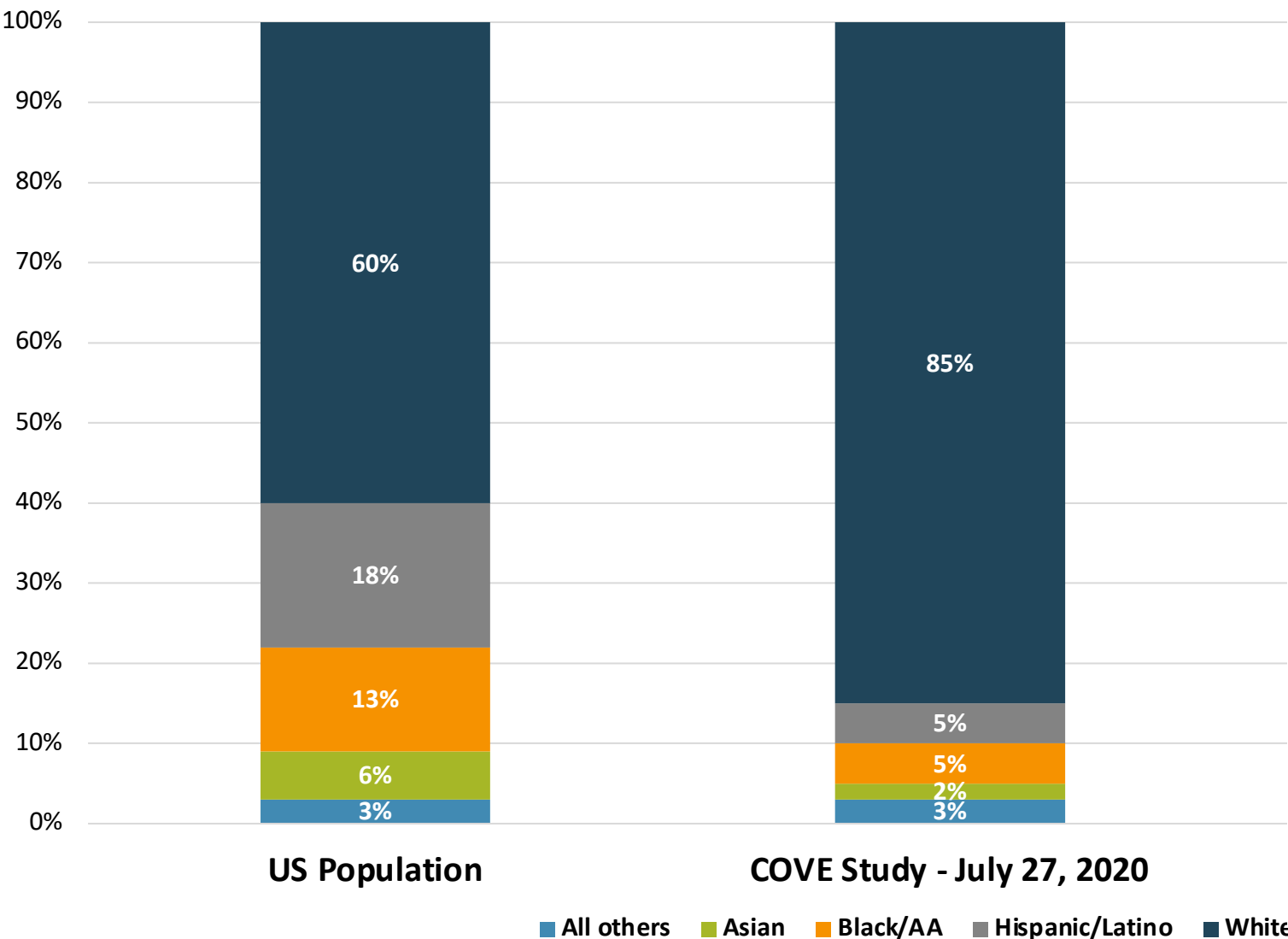
Note: Respondents who did not give an answer are not shown.

Source: Survey conducted Sept. 8-13, 2020.

"U.S. Public Now Divided Over Whether To Get COVID-19 Vaccine"

PEW RESEARCH CENTER

Lack of Diversity in COVID-19 Vaccine Trials: Moderna COVE Trial vs. US Population



How do we Address Hesitancy about Participating in Research on COVID-19 Vaccines and Therapeutics?

Consultation from ID (Drs. Landovitz and Currier) to the Community Engagement and Research Program in June 2020

- How can we ensure representation in the UCLA COVID-19 vaccine trials?
...and by the way, the trial is scheduled to start in a month?

COVID-19 Community Consultant Panel

Los Angeles COVID-19 Vaccine Trials

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

Partnerships, Stakeholders, & Organizations Represented

UCLA CTSI

- Clinical & Translational Research Center (CTRC)
- Community Engagement & Research Program (CERP)

Clinical Trials

- UCLA CARE Center
- The Lundquist Institute, Harbor-UCLA Medical Center
- UCLA Vine Street Clinic

Community Stakeholders

- Racial/ethnic and socioeconomic diversity of LA County



Deliberative Community Engagement (DCE)

- Qualitative research method designed to obtain opinions from lay individuals on complex topics with which they are unfamiliar

COVID-19 Community Consultant Panel Goals

Short term:

Help us ensure that the Los Angeles County COVID-19 vaccine trial participants represent the diversity of individuals at risk across LA County

Long term:

Once a vaccine is available for wider use, advise and consult on vaccine acceptability and concerns

What is Community Expertise?

- Perspectives on cultural factors and community norms
- Questions and concerns the community may have
- Frame the language, message, and communication strategies so that they resonate with the community



COVID-19 Community Consultant Panel (CCP): Deliberative Community Engagement

Rapid implementation timeline - 6 weeks

- CERP first consulted for community engagement strategies in vaccine clinical trials at UCLA
- Obtained recommendations from community leaders for an advisory panel and sent invitations
- First CCP meeting via zoom

Participation: 8-weeks to provide input on ongoing/new vaccine clinical trials

- 2-hrs per week (meetings scheduled around work)
- Compensation for intensive and rapid participation: \$200/ hour

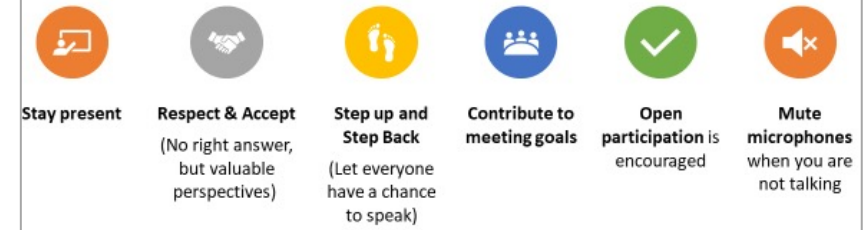
Rapid development of introductory materials:

- Clinical trial briefing booklet
- Website with resources, news, videos

Weekly approach:

- Information session → Q&A → Structured Discussion

Setting Collaborative Ground Rules Ground rules



Dedicated Website



Briefing Booklet: Role of Community, Clinical Trials, and Vaccine Development

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Please contact Eno Nwagwu via email at enwagwu@mednet.ucla.edu or phone at 310-909-5289

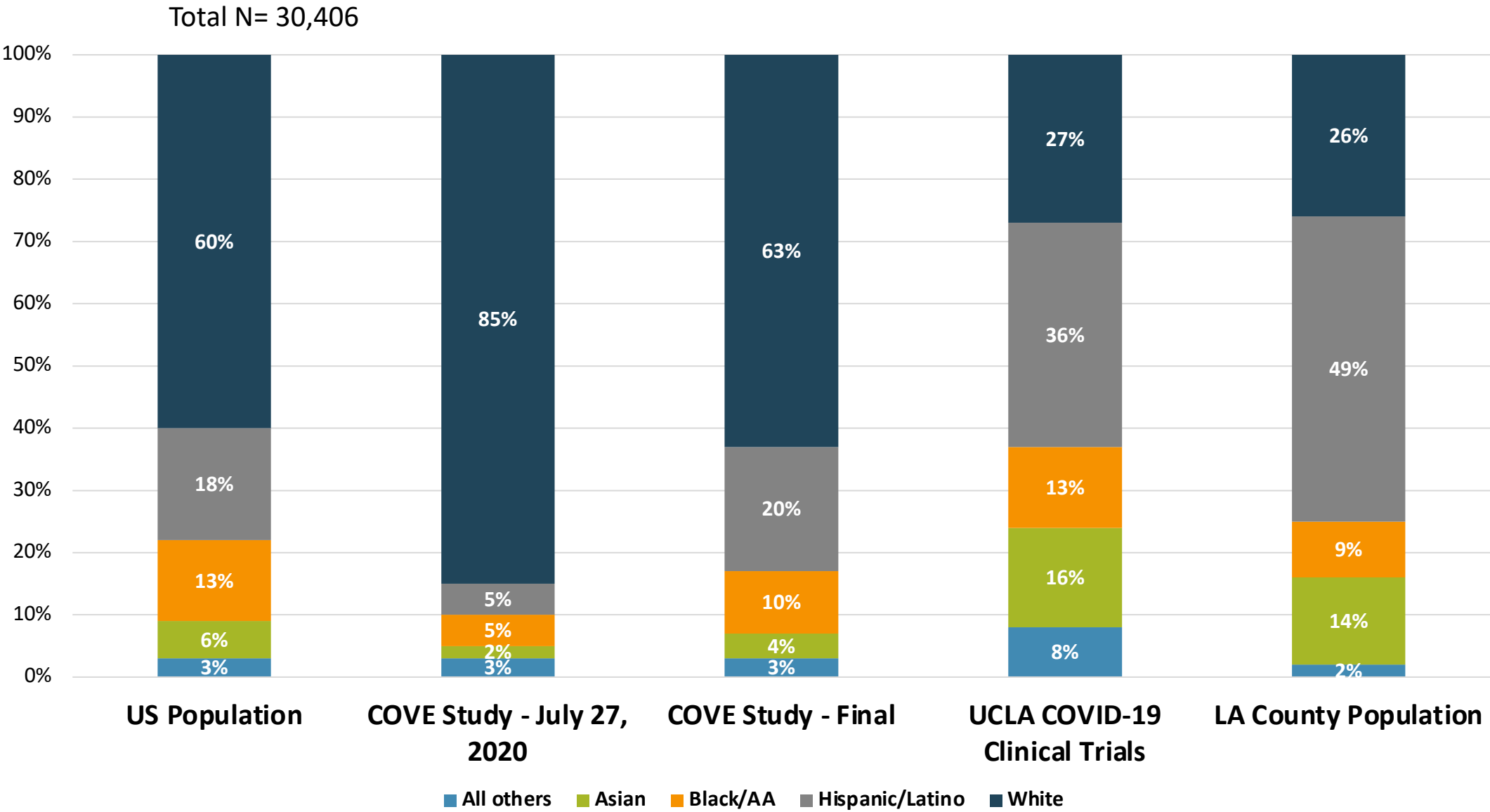
CCP Recommendations / Considerations

Community Panel Recommendation	Modifications Made / Discussion Points
Increase Trust in the Process:	
<ul style="list-style-type: none">Enhance transparency	<ul style="list-style-type: none">Where the trials were and who ran them (academic vs. private)
<ul style="list-style-type: none">Need for trusted messages	<ul style="list-style-type: none">They wanted clear information and access to resources about COVID-19, vaccine trial process, and vaccinesIdentified trusted sources in their communities to provide clear information about COVID-19, clinical trials, and vaccines
<ul style="list-style-type: none">Recruitment/outreach for diverse communities	<ul style="list-style-type: none">Multiethnic media and venues for trusted communicationTailoring approaches and methods (face-to-face, visual, written, social media)

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<ul style="list-style-type: none"> Recruitment/outreach for diverse communities 	<ul style="list-style-type: none"> Multiethnic media and venues for trusted communication Tailoring approaches and methods (face-to-face, visual, written, social media)
Enhance accessibility of the trial:	
<ul style="list-style-type: none"> Provide transportation for trial participants 	<ul style="list-style-type: none"> Additional funding identified to provide transportation for clinical participants (both routine visits and “sick day visits”).
<ul style="list-style-type: none"> Health care for uninsured participants if adverse reactions/COVID-related illness 	<ul style="list-style-type: none"> Detailed information on participant coverage for adverse reactions through the trial
<ul style="list-style-type: none"> Increase trial sites in minority communities 	<ul style="list-style-type: none"> Recommended community clinics, mobile trial sites
<ul style="list-style-type: none"> Cultural competence & customer service 	<ul style="list-style-type: none"> Participants should be welcomed, asked their gender pronouns, shown the restrooms, given food and drink, and be thanked

Diversity: LAC Clinical Trials



Understanding COVID-19 Vaccine Decision-Making in Multi-Ethnic Communities

Unpacking Vaccine Hesitancy



Original Investigation | Public Health

COVID-19 Vaccine Decision-making Factors in Racial and Ethnic Minority Communities in Los Angeles, California

Savanna L. Carson, PhD; Alejandra Casillas, MD, MSHS; Yelba Castellon-Lopez, MD, MS; Lisa N. Mansfield, PhD, MSN, RN; D'Ann Morris, MPA; Juan Barron, BA; Ejiro Ntekume, MPH; Raphael Landovitz, MD, MSc; Stefanie D. Vassar, MS; Keith C. Norris, MD, PhD; Steven M. Dubinett, MD; Nanibaa' A. Garrison, PhD; Arleen F. Brown, MD, PhD

Understanding COVID-19 Vaccine Decision-Making

November-January 2021 Multiethnic Focus Group Study

Objectives:

- Amplify the voices of community members to understand potential barriers and facilitators to COVID-19 vaccine readiness
- Inform public health initiatives once a vaccine widely available

Methods: Thirteen 2-hour focus groups with members of LA County communities at high-risk for COVID-19. Led by trained facilitators and community representatives who self-identify with each ethnic group. ***Participants asked to contribute and reflect as individuals and experts from their communities.***

- Race/ethnicities facing a high burden of COVID-19 and related comorbidities:
Hispanic/Latino **African American/Black** **American Indian/Native American,**
Filipino **Pacific Islander**
- A majority of participants (73%) resided in **high poverty zip codes** (56%) or were **essential workers** (49%)



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

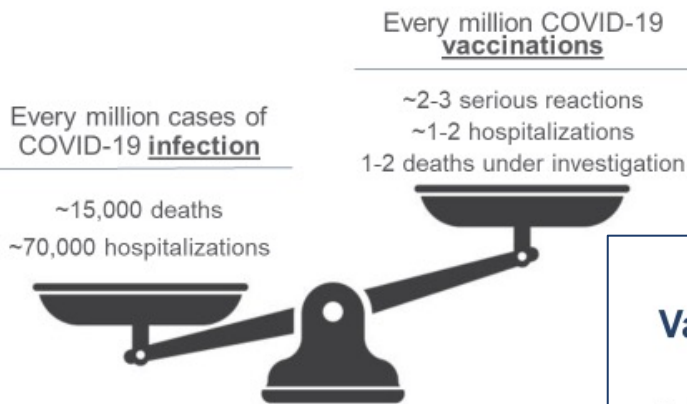
- Vaccine hesitancy is a **complex, multifaceted concept** that encompasses **deliberation, accessibility, and acceptability**.
- **Reduce structural barriers** *in parallel with* vaccine outreach and engagement.
- **Collaborate with, invest in, and empower** trusted community leaders to share information 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.



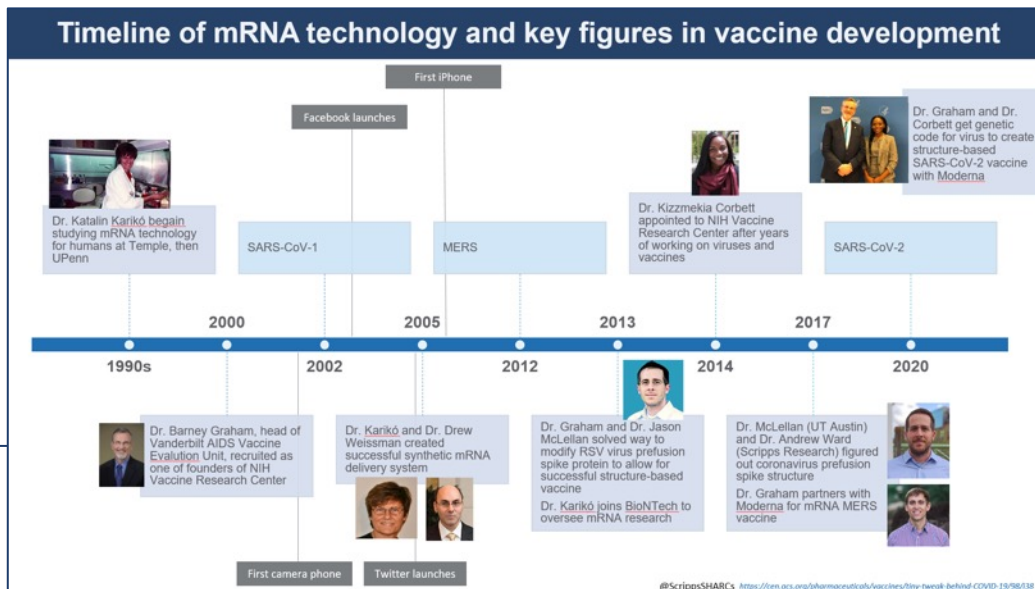
Outreach Materials Derived from Focus Groups

- Addressed misconceptions as well as 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



Moderna and Pfizer vaccine each reported 10 serious allergic reactions out of 4 million doses (as of 1/11/21)



COVID-19 Vaccine Information: Answers to Important Questions!

Pfizer & Moderna

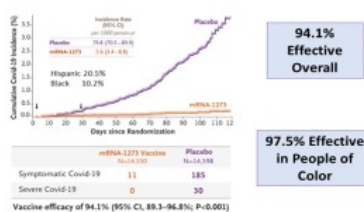
Why should I get vaccinated?

UCLA

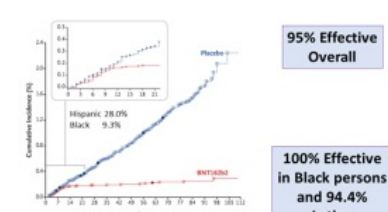
January 2021

Vaccine Effectiveness: Race/Ethnicity Data

Moderna Covid Vaccine Trials



Pfizer Covid Vaccine Trials



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 (65+, over 85% effective)
- Race/ethnicities (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 prolong your immunity.

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

Moderna 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%, 9.8%), Hispanic/Latino (20.5%, 26.2%), Multiracial (2.1%, 2.5%) and Pacific Islander (0.2%, 0.2%), respectively.

Which vaccine choice?

- Both Pfizer and Moderna are about 95% effective
- At this point, you cannot choose the same as someone else only vaccine of age. Pfizer doses, space

Is the vaccine safe for someone like me?

Not currently, but to get the vaccine, you increase your risk of complications.

Should I get the COVID-19?

Yes. Protection can prolong your

Community Engagement Alliance (NIH CEAL)

Objectives

1. To conduct **urgent community-engaged research and outreach focused on COVID-19 awareness and education to address the widespread misinformation** about COVID-19 and promote an evidence-based response to the disease;
2. To promote and facilitate **inclusion of diverse racial and ethnic populations in COVID-19 clinical trials (prevention, vaccine, therapeutics)**, reflective of the populations disproportionately affected by the pandemic.

Awardees:

1st wave: Alabama, Arizona, California, Florida, Georgia, Louisiana, Michigan, Mississippi, Missouri, North Carolina, Tennessee, Texas

2nd wave: Arkansas, Colorado, DC Metro, Illinois, Massachusetts, New Mexico, New York, Pennsylvania, Puerto Rico



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

SHARE TRUST ORGANIZE PARTNER STOP COVID-19 CA

THE COVID-19 CALIFORNIA ALLIANCE

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



- 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**

Aims: Academic + Community partnered teams:

- Increase Knowledge; Decrease Dis/Mis-information
- Diverse inclusion in COVID clinical trials
- Uptake of vaccines and therapeutics across high risk communities in California

Strategies:

- Bidirectional knowledge exchange
- Co-development of culturally-tailored, community-relevant strategies
- Sustainable practices
- Evaluate effectiveness of strategies

STOP COVID-19 CA: Site Projects

Information Needs | Trial Participation | Vaccine Hesitancy

Trusted Education/Outreach

- CHWs
- Community Organizations
- Local Media
- Health Fairs, town halls, listening sessions
- Visual Arts

Qualitative Research

- Focus groups in multiethnic communities
- Deliberative community engagement

Capacity Building

- Training (CHWs, Media)
- Education tailored for population

Ethnic Media Outreach

- Spanish/Black radio
- Ethnic newspapers

Community surveys/ needs assessments

- Surveys
- CHIS (CA Health Interview Survey)
- Educational assessment

Clinical Trial Community Engagement

- Studios
- Community advisory boards
- Recruitment / outreach

California Health Interview Survey (CHIS)

- Conducted in English, Spanish, Cantonese, Mandarin, Korean, Tagalog and Vietnamese
- COVID-19 Survey and Dashboards
- Asian and NHPI Discrimination

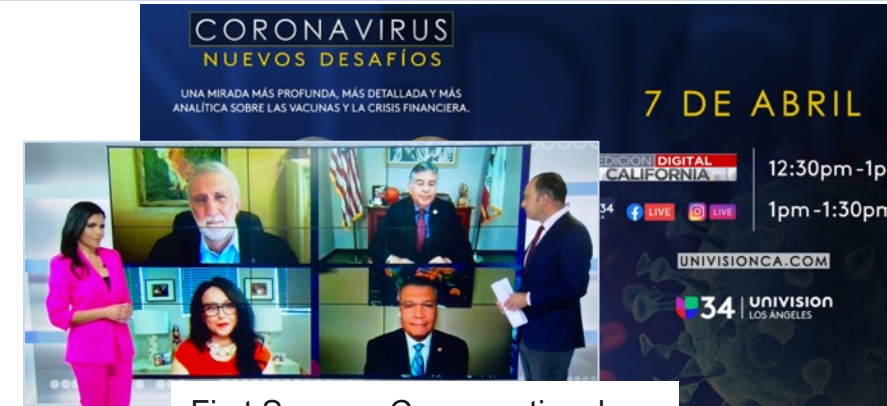
Populations / Communities

- Latinx – including monolingual Spanish
- Black/African American
- Asian – Filipino, Chinese, Vietnamese
- Native Hawaiian / Pacific Islander
- American Indian / Indigenous
- Essential Workers, e.g., farmworkers
- Immigrant
- LGBTQ
- Low-income

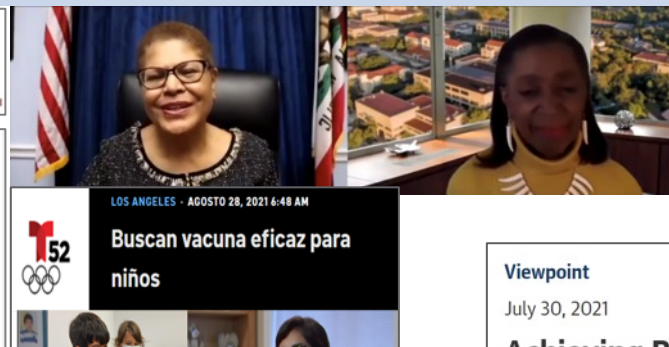
STOP COVID-19 CA: The COVID-19 California Alliance

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



First Samoan Congregational Christian Church of San Diego



Llevará UC Davis pruebas de COVID-19 gratis a trabajadores agrícolas del Valle Central

Posted on **octubre 1, 2020**

"Estamos llegando a donde están las necesidades, y las necesidades momento, basándonos en los datos sobre el número de casos, el número de muertes, la propagación, los brotes del virus que están ocurriendo."

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



Get out the Vaccine Campaign (GOTV): Los Angeles CBOs

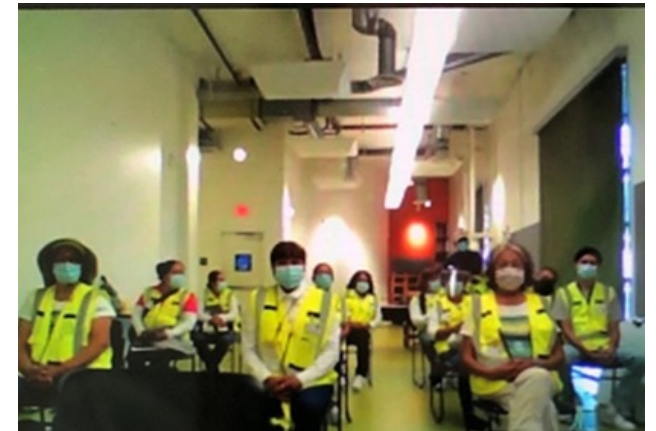
- AMP LA
- Antelope Valley Partners for Health
- Barrio Action Youth & Family Services
- Black Women for Wellness
- CD Tech
- Coalition for Responsible Community Development (CRCD)
- Conaxion Inc.
- Esperanza Community Housing
- Kutturan Chamoru Foundation
- LBBF Shortstop (w/ Elite Skills Development)
- Legacy LA
- Mexican American Opportunity Foundation (MAOF)
- Parents, Educators/Teachers & Students in Action
- South Bay Center (SBCC)
- South Central United
- Urban 360
- Watts Labor Community Action Committee (WLCAC)



Bidirectional Exchange in GOTV

Lessons learned from CBOs to improve implementation

- Feed back mis/dis-information on what they are hearing and where it is from
- Crowd canvassing events *in addition to* door-to-door:
 - Local events, churches, health fairs, swap-meets, pop-up vaccination sites, etc.
 - Use of mass texting for pop-up events
- Creative strategies for engagement
 - “Vaccine ready” ambulance
- Lived experience
- Personalized outreach and storytelling: “...*why I understand your concerns, and why my story relates to yours...*”
 - Esperanza’s 15 Canvassers – importance of lived experience
 - 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

GOTV: Success Stories



Monic Uriarte



Get Out The Vaccine Campaign (GOTV): Results to Date

Outreach as of 9/20/2021

- **1.6M** Doors canvassed
- **>500K** phone calls
- **>1.2M** text messages
- **>100k** conversations at events (crowd canvassing)
- **39,952 individuals registered for vaccine**

Research and Evaluation

- Surveys with CBOs and canvassers on experiences with program and COVID-19
- Secondary data analysis – geographic analyses
- Social determinants – food insecurity, rental relief, employment assistance

Investigator Development and Support

- Junior faculty, fellows, graduate students, and undergraduates



Canvassers from Esperanza Community Housing 6/8/2021



LA Trade Tech President Dr. VanderWoude 6/8/2021
with CERP team members

To Address COVID-19* Misinformation, Reduce Disparities, and Reach Underrepresented Communities:

- Address challenges directly: time, appropriate funding
- Paradigm shift: “Hard to Reach” → “Hardly Reached” (*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 preterm birth or*

Acknowledgments

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